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ABSTRACT

This final report describes activities of Project INSITE, a 3-year home intervention program delivering services to infants, toddlers, and preschoolers with deaf blindness or other multidisability sensory impairments. The family centered model features the use of early intervention professionals known as parent advisors who visit homes weekly to work with families and function as team members in preparing for transition to school programs and the development of Individualized Family Service Plans and Individualized Education Programs. Additional program features include material development, provision of follow-up and technical assistance, training of trainers, and systematic evaluation. The Project has adapted to changing trends by providing statewide coordinators of implementation plans for low incidence handicapping conditions with capacity building technical assistance. Project INSITE has provided direct services to 880 families, training to 440 professionals in 12 states, and technical assistance to more than 180 agencies. The Project has also developed several resource manuals for families as well as training materials and videotapes. Appendices include evaluation summaries, INSITE national data report for 1991-92, title pages of products, the training format, and a list of 19 references. (DB)

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FINAL REPORT

to

U.S. Department of Education
Office of Special Education Programs
Early Education Programs for Children With Disabilities

CFDA #84.024D

By

Project INSITE Outreach
Award #H024D90022

Outreach Services to Stimulate Home-Based Services for Infants, Toddlers, and Preschool-Aged Children with Deaf-Blindness and Multihandicap Sensory Impairments

Department of Communicative Disorders
Utah State University
Logan, Utah 84322-1900

March 30, 1993

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II. ABSTRACT

Project INSITE was developed as a U.S. Office of Special Education Early Education demonstration model between 1981 and 1994. The home intervention services of INSITE delivered to infants, toddlers, and preschoolers with multidisability sensory impairments and their families were continued after the demonstration period by the state of Utah through the State Schools for the Deaf and the Blind and in several locations throughout the United States. INSITE became an Outreach program in 1984 and has developed an effective outreach model. INSITE was validated in 1989 by the Program Effectiveness Panel, National Diffusion Network, U.S. Department of Education.

The INSITE Model is a family centered model. In this model, an early intervention professional, called a parent advisor, goes to the home weekly to work with the family of a child with deaf-blindness or multidisability sensory impairment. The parent advisor has the INSITE Resource Manual to use as a guide and resource. The parents and parent advisor work as team members with other appropriate professional personnel in determining goals, writing and reviewing the Individualized Family Service Plan (IFSP) or Individualized Educational Plan (IEP), carrying out and monitoring activities, and preparing for transition to school programs.

With the support of the U.S. Office of Special Education and National Diffusion Network, the INSITE Model has been adopted throughout the United States by a variety of agencies serving very young children with multidisability sensory impairments in specialized settings. With the implementation of P.L. 99-457 in 1986 and subsequent amendments included in P.L. 102-119, children with low incidence disabilities are beginning to be served within early intervention/early childhood programs for all infants, toddlers, and preschoolers with disabilities. This change in service settings has opened a new training arena and spurred more demand for INSITE Outreach services.

Project INSITE Outreach has seven major innovative features: (1) it uniquely meets the developmental needs of very young children who are multidisabled and sensory impaired that can be met in no other way, (2) it encompasses a complete delivery system of family centered intervention for infants, toddlers, and preschoolers who are multidisabled and sensory impaired and their families, (3) it uses an innovative awareness and training

approach to meet the changing audiences of direct service providers and their programs, (4) it has developed and continues to develop, state-of-the-art materials which support early interventionists and the families they serve, (5) it has developed a system of providing follow-up and technical assistance to sites, (6) it has provided a means by which local INSITE trainers can be trained to provide INSITE training to new professionals in programs throughout their state, and (7) and it has developed a system for evaluating the effect of the INSITE Model on child and family progress as well as the effectiveness of the outreach process.

The goal of the INSITE Outreach project is to build the capacity of states, local education agencies, and other service agencies to implement the INSITE Model, a proven model that will improve early intervention services to infants, toddlers, and preschool-aged children with multidisability sensory impairments and their families.

When the INSITE service model is delivered through local school districts and other early intervention agencies typical in today's service delivery program, the personnel who provide the direct services are typically not those with specialization in sensory impairments combined with other handicapping conditions. Instead they have generally received cross categorical training with only limited exposure to sensory impairments. Thus, INSITE training for personnel in these programs has become even more important. Through past experience gained by Project INSITE outreach staff, unique training requirements which consider the background of participants, logistical challenges and level of agency suppor have been addressed.

In the past 5 years, a completely new educational structure has evolved in State Lead Agencies for children with disabilities birth through 5 years of age. At this date all states have mandated services for ages 3 to 5 and 6 to 21, and approximately half of the states have mandated programs for the birth to 2 children. The State Health Departments have generally assumed the leadership for the birth to age 2 programs while the State Departments of Education are typically responsible for the early childhood programs of age 3 to 5 programs. It has been critical for Project INSITE to adapt to these new educational structures.

Project INSITE has been able to successfully adapt to this trend toward implementation from the state level down versus the agency-level-up approach used in past years. Project INSITE has been able to offer statewide coordinators assistance as they

provide services through statewide implementation plans for low incidence handicapping conditions. The result has been that states and other local agencies have begun building their local capacity to provide services.

Training to the unique needs of INSITE direct service providers who come from diverse backgrounds and educational settings has been challenging and at the same time has caused the INSITE outreach staff to be aware of the necessity of maintaining state-of-the-art materials and training procedures. INSITE training requires 6 intensive days. The delivery of training typically is accomplished through two 3-day workshops. Following this format, INSITE national trainers are now field testing new approaches that increase the rigor of the training, give agencies more flexibility, and more closely align Project objectives with participant expectations.

The population INSITE serves is unfortunately growing, due to several societal changes occurring including drug use during pregnancy, teenage pregnancy, and medical advances in neonatal care. It is clear from the letters of request for services that there are many state and local agencies needing INSITE training, materials, and assistance in developing effective early intervention services for these children and their families.

Over the last 3 years of this grant, the direct impact of the project has been that the families of approximately 880 new infants, toddlers, and preschoolers have been receiving services. At least 440 professionals in 12 states have received training in the INSITE Model through the project staff. An indirect impact has been that approximately 700 new professionals have received INSITE training and materials through local INSITE trainers in 14 states. This has affected the lives of hundreds of families. Twenty-nine new local trainers were trained by the project. Three new national trainers were added to the cadre of national trainers, bringing that total number to 11. In addition, 1,500 families and 400 professionals in continuing INSITE agencies have received ongoing assistance. Approximately 550 professionals in more than 180 agencies throughout the country have received technical assistance through the newsletters, phone contacts, and onsite and regional workshops that have been provided through the project's resources.

These professionals and the families they serve have also benefitted from the new state-of-the-art materials that have been developed with the help of the project's resources. These include such items as: 1) a new resource manual for families of preschoolers with

vision impairments, 2) topic summary/challenge sheets to go with the INSITE manual, 3) a parent resource notebook, 4) a monograph on children with special health care needs, 5) a new resource manual on deaf-blindness, 6) new training materials and videotapes, and a number of other materials as well. In addition, a newly funded model inservice training grant for professionals working with preschool-aged children who are blind and vision impaired came into being through the efforts of INSITE Outreach.

INSITE is a program that is and can be implemented across a variety of settings. INSITE was developed because there was a need for an effective way to provide services to the families of infants and very young children with multidisability sensory impairments. INSITE met that need and continues to do so today.

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IV. GOALS AND OBJECTIVES OF THE PROJECT

The purpose of the Project INSITE Outreach is to stimulate and assist agencies to develop and implement home intervention services to presently unserved or underserved infants, toddlers, and preschoolers with multidisability sensory impairments and their families. There are seven objectives:

1. To create appropriate public, professional, and agency awareness of the need for home intervention services to infants, toddlers, and preschoolers with multidisability sensory impairments and their families through the INSITE Model.

2. To stimulate agencies to commit resources to the development and implementation of services to infants, toddlers, and preschoolers with multidisability sensory impairments and their families through adoption of the INSITE Model.

3. To provide training to adoption agencies to enable personnel to implement INSITE curriculum and procedures in conjunction with their state plan to serve young children with disabilities and their families.

4. To assist agencies in implementation of the INSITE Model.

5. To evaluate the effect of the INSITE Model on child and parent progress and the effectiveness of the outreach process.

6. To develop instructional, curricular and training materials for use with parents in the home and in training personnel in implementing the INSITE Model.

7. To assist states in developing full, coordinated services for families of infants, toddlers, and preschoolers with multidisability sensory impairments, to implement Public Law 99-457.

A final progress report on each of the seven objectives listed above will be provided in section six of this final report.

V. CONCEPTUAL FRAMEWORK FOR THE PROJECT

INSITE outreach focuses on two major areas of need. The first area has to do with the handicapping conditions that the service model treats and associated service delivery model needs. The second area relates to effectively transferring an early intervention model

through outreach to local agencies, and subsequently to replicate effective services for children and families.

These needs will be discussed below. How the Project met these needs will be discussed in section seven.

A. The Effects of Multidisability Sensory Impairments on the Child and Family

The type of child served by INSITE programs is defined as one who is deaf-blind, blind or vision impaired with other disabilities, or deaf or hard of hearing with other disabilities. These sensory impairments are perhaps the least understood of all handicaps, and the most devastating to the development of the child. The cross-developmental effects of a combined sensory loss are staggering (Collins, 1988). The effects are not merely additive, but multiplicative and cumulative (McInnes & Treffrey, 1982).

Vision and hearing are the primary senses that put a child in touch with the world beyond his or her reach and through which the child can most efficiently learn through modeling. When one or both of these senses is impaired, opportunities for secondary and tertiary learnings are severely restricted. Communication deficits and mobility limitations are two obvious consequences of a multidisability sensory impairment. Other delays typical in these children are disruptions in fine motor, cognitive, and social-emotional development (Bullis & Bull, 1986; Chen, Friedman, & Calvello, 1988; Correa, 1987; Fox, 1983; Gothelf, Pikhye, & Silberman, 1988; Murdoch, 1986; Watkins, 1983; Writer, 1984.)

The effect of the infant or child with a multidisability sensory impairments (MDSI) on the family can be one that adds psychological and financial stress. The family may be in need of guidance and support (Smith, 1988). Establishment of meaningful communication between parent and child as well as a nurturing environment are critical. Extensive time spent in ICUs, loss of the idealized child, infant unresponsiveness, extensive medical intervention, lack of sensitivity by professionals and many other abnormal occurrences combine to compound stress to family relationships. Parents require time to adjust and organize their lives after the birth of a child with a disability.

B. The Need for Intervention

The effects of multihandicapping conditions on the developing child and the family create a critical need for intervention. Project INSITE recognizes this and addresses five key needs. These needs and the INSITE approach to meeting them are strongly supported by research, as described briefly below. References are in Appendix A.

1. The first is the need for *early home intervention*. Infants and toddlers with multidisability sensory impairments must receive early intervention if their development is to be facilitated. The home is widely recognized as the place where early stimulation should occur, if possible. Daily experiences that are ideal for stimulation occur in this natural environment, such as mealtime, dressing, and play. There are additional advantages of the home as the primary intervention setting. Activities can be adapted to the culture and values of the family. Other family members can be involved. Home visits can provide a less threatening setting for the family, give a more realistic picture of family dynamics and emotional needs, and provide a comfortable atmosphere for support. Home visits seem to result in a higher rate of parent participation (Schow & Watkins, 1989).

2. The second is the need for *family-centered intervention*. A family centered approach to intervention is necessary, not only because of legal mandates (Part H of the Individuals with Disabilities Education Act (IDEA)), but because it will facilitate (a) an understanding of the child as part of a family system, (b) the identifying of family concerns and priorities for service, (c) the identifying of family resources and supports that promote family adaptation, and (d) the expanding of a base for evaluating services (Bailey & Simeonsson, 1988).

3. The third is *the need for services that address all aspects of the child's development and environment*. The IDEA stipulates attention to and service provision for all aspects of the child's life. The effects of multidisability sensory impairments on various developmental areas was discussed earlier. The assessment of child characteristics and needs in all domains (i.e., communication, motor, socialization, adaptation, cognition, sensory) must be culturally competent and adapted to each individual family and the environment in which they live and function (Anderson & Goldberg, 1991; Barnett, Macmann, & Carey, 1992; LeLaurin, 1992). Child skills, needs, and characteristics likely to affect family functioning must be determined. Developmental habilitation and stimulation must then be given as appropriate (Bailey & Wolery, 1989).

4. The fourth is *the need for transitioning the child from home to school-base programming*. A smooth and effective transition must involve the parents, parent advisors, teachers and other members of the multidisciplinary team who address the gathering of information from and about the family, child assessment, staff/parent knowledge of programs, parent involvement, cooperative decision making, program modification and ongoing communication. This ensures

continuous age-appropriate service for the child and positive, productive program-change experiences for family members.

5. *The need for cost-effective early intervention.* Special education programs for preschool children with disabilities must be cost-effective. A comprehensive review of the research in this area indicates that early intervention programs in general provide long-term human and economic benefits. For example, an extensive review was conducted on the costs of special education based upon age of entry into the program. The data indicated that delaying services resulted in more children requiring more special services at higher costs (Colorado Department of Education, 1984). Early education programs in general have been shown to be cost-effective; the INSITE model, in particular, has been verified as a cost-effective service delivery model.

C. Concepts Underlying the INSITE Outreach Project

The INSITE early home intervention program was developed to meet the needs of the family and the child with multidisability sensory impairment. There is a further need for a system to transfer that effective program to state and local agencies which serve children and families. State and local educational agencies, Part H and Section 619 coordinators continue to request INSITE training and implementation assistance. INSITE Outreach provides an effective process for awareness, dissemination, training, technical assistance, evaluation, and product development which meets their needs.

With the support of the EEPCD, the INSITE Model has been adopted throughout the United States by agencies serving very young children with multidisability sensory impairments and their families in special programs. With the implementation of P.L. 99-457 and P.L. 102-119, children with low incidence disabilities are now also beginning to be served within early intervention/early childhood programs for all infants, toddlers and preschoolers with disabilities. It should be noted that except for the larger metropolitan areas, there are usually only a few children with multidisability sensory impairments in each local early childhood or parent-infant program. This change in service setting has opened a new arena and demand for INSITE Outreach services.

When the INSITE service model is delivered through local school districts and other early intervention agencies typical in today's service delivery, the personnel who provide the direct services are typically not those with specialization in sensory impairments combined

with other handicapping conditions. Instead, they have generally received cross categorical training with only limited exposure to sensory impairments. In addition, access to other professionals who might have experience and training with this low incidence population is often limited. Thus, INSITE training for personnel in these programs becomes vitally important and enables them to provide more appropriate services to children (birth to 3) with multidisability sensory impairments and their families.

In responding to the desire for coordinated statewide services and systemic change, INSITE Outreach conducts awareness and dissemination, and all planning, training and technical assistance, through close cooperation with state coordinators of education and coordinators of Part H and Section 619 programming.

Project INSITE Outreach offers critical training features to school districts and other agencies serving infants, toddlers, and preschoolers with multidisability sensory impairments. These training features include how to work with parents and other caregivers in the home and other settings outside the school. The training includes specific techniques and activities to use with this population as they relate to their unique needs. These elements included in the training are necessary to ensure optimal programming and to ensure that Goal #1 of America 2000 is achieved. This goal states that *all* children will enter school ready to learn. It is imperative that children with multidisability sensory impairments receive the programming and materials offered through Project INSITE Outreach, for these children are part of the realization of this goal.

VI. DESCRIPTION OF THE DEMONSTRATION AND OUTREACH MODELS AND OUTREACH ACTIVITIES AND ACCOMPLISHMENTS

A. Description of Proven Demonstration Model--The INSITE Model

The INSITE Model is a family support model for families of infants, toddlers, and preschoolers with multidisability sensory impairments. The rationale for designing a program specifically for this population is that a multisensory or multidisability sensory deprivation has a profound effect on the child and family that cannot be addressed adequately by non-categorical programming.

INSITE model services are delivered in the home to the family and in alternate day care settings to other significant caregivers. An early intervention professional, called a parent advisor, goes to the home on a weekly basis to work with the families, providing support and information, and enhancing the family's development of skills to facilitate their child's development. The parents determine their resources, priorities, and concerns. With the parent advisor, they develop family/child goals and select experiences and activities in which to practice new skills. The parent advisor shares information and models skills for the parents with the child, keeping in mind the unique structure and environment of the family. The parents then use the new information and skills to facilitate development in the child as they interact with him or her.

The parent advisor also helps the family facilitate interdisciplinary coordination among all professionals and agencies serving the family. The parents and parent advisor work as team members with other appropriate professional personnel in assessing the child, writing and reviewing the IFSP, carrying out and monitoring goal-oriented activities, and designing transition procedures.

The resource manual which the parent advisor uses was developed by INSITE staff. It has been designed around several major developmental areas. The Communication Program enables the family to establish a communicative relationship which provides a base for the child's developmental progress. The Hearing Program helps the parents manage their child's hearing aid usage and facilitate auditory development. The Vision Program helps the parents understand visual loss and facilitate the child's visual development. The Motor Development Program assists parents in facilitating the child's use of his or her motor capacity. The Cognition Program helps parents foster cognitive development in the child. The Developmental Resources Section provides additional information and activities for daily care/self care, gross and fine motor development, and social-emotional skills. The Parent Readiness guide of the resource manual helps the parent advisor make an ecological observation and, along with the parents, discover and access resources to meet family-identified concerns. Together, the parents and parent advisor decide which developmental areas to work in, then decide on goals, objectives, and facilitative activities appropriate to the family. They keep records of their progress and the progress of the child, and make adaptations as needed.

In its essence the INSITE Model is a family-centered model. The child is identified at the earliest possible age and the parents receive support, information and training concerning the disabling conditions, special considerations about parenting their child, and working collaboratively with providers of services. The parent advisor adapts the programming as appropriate to cultural background, values or other considerations. The strength of an INSITE home-based program is the effective involvement of the family in all aspects of the service delivery model. The parents fully participate in establishing family focused goals and the IFSP. They participate in service coordination. They periodically review progress to establish new goals, make a communicative methodology decision, and help decide when program goals are met and home services are no longer needed. They cooperate in the transition of their child from home programming to center-based programming. As a result of early intervention, the family attains an acceptance of the child and the disabilities; understands and uses the programming needed by the child; establishes a communicative, nurturing environment for the child; and is equipped to continue service coordination as the child transitions to other service settings.

The three major components of the INSITE model are Administration, Direct Services to the Family, and Supportive Services. Figure 1 on the following page illustrates the complete INSITE Model.

Figure 1

THE INSITE MODEL

ADMINISTRATION

Identification	Family Directed Assessment	Program Management	Training and Supervision	Transition
Screening	Multi-Disciplinary Assessment of the Child and of Family Resources, Priorities, and Concerns	Coordination with Statewide System	Staff Training	Service Option Planning and Development
Public Awareness		Staff Selection	Inservice Training	Transfer of Information
Referral System		Service Delivery Model	Supervision System	Adherence to Local Procedures
Intake System	Family Focused Interview	Service Coordination		Post-Placement Follow-up
	Family Goal Setting	Interagency Cooperation		
	IFSP	Program Evaluation		
	IEP	Home Visit Procedures		
		Budget		

DIRECT SERVICES TO THE FAMILY

Family Readiness	Communication Development for the Family	Developmental Areas	Team Management	Family Support
Caring for the Child	Creating an Environment that Fosters Communication	Vision Program	Parent-Professional Partnership	Psycho-Emotional Support
Meeting Family Survival Needs		Hearing Program	Consultation and Planning	Accessing Services
Emotional Readiness for Information	Informal Communication	Motor Program	Periodic Assessment	Working with Intervener
	Formal Communication	Cognition Program	Periodic Staffings	Cultural Competence
	Other Communication Modes	Self Help, Social and Tactile Skills		

SUPPORTIVE SERVICES

Medical	Educational/Clinical	Logistical	Psychological	Community
Otolaryngology	Audiology	Video Equipment	Consultative	Church
Ophthalmology	Physical Therapy	Hearing Aid Loan System	Parent/Family	Cultural Resources
Pediatrics	Occupational Therapy	Parent Materials	Parent Advisor	School
Nursing	Speech/Language	Adaptive Equipment	Parent Groups	Respite Care
	Vision	Parent Library Loan		Mental Health
	Hearing	Low Vision Aid Loan System		Social Services
	Orientation and Mobility	Toy Lending Library		Foundations

Financial	Intervener	Transitioning
Public Service Agencies	Selecting, Training and Using Intervener	Assistance to Parents
Private Agencies		Preparation of Child

B. Description of Outreach Model

The INSITE Outreach design includes all the activities specified in Priority 2, Outreach Projects and is organized as follows to facilitate optimal capacity building:

1. Coordination with Lead Agency for Part H and with State Educational Agency for Preschool Special Education.

2. Awareness and Dissemination
   Product Development and Dissemination

3. Site Development and Assistance in Replicating the Model

4. Training
   Follow-Up Activities and Technical Assistance
   Evaluation

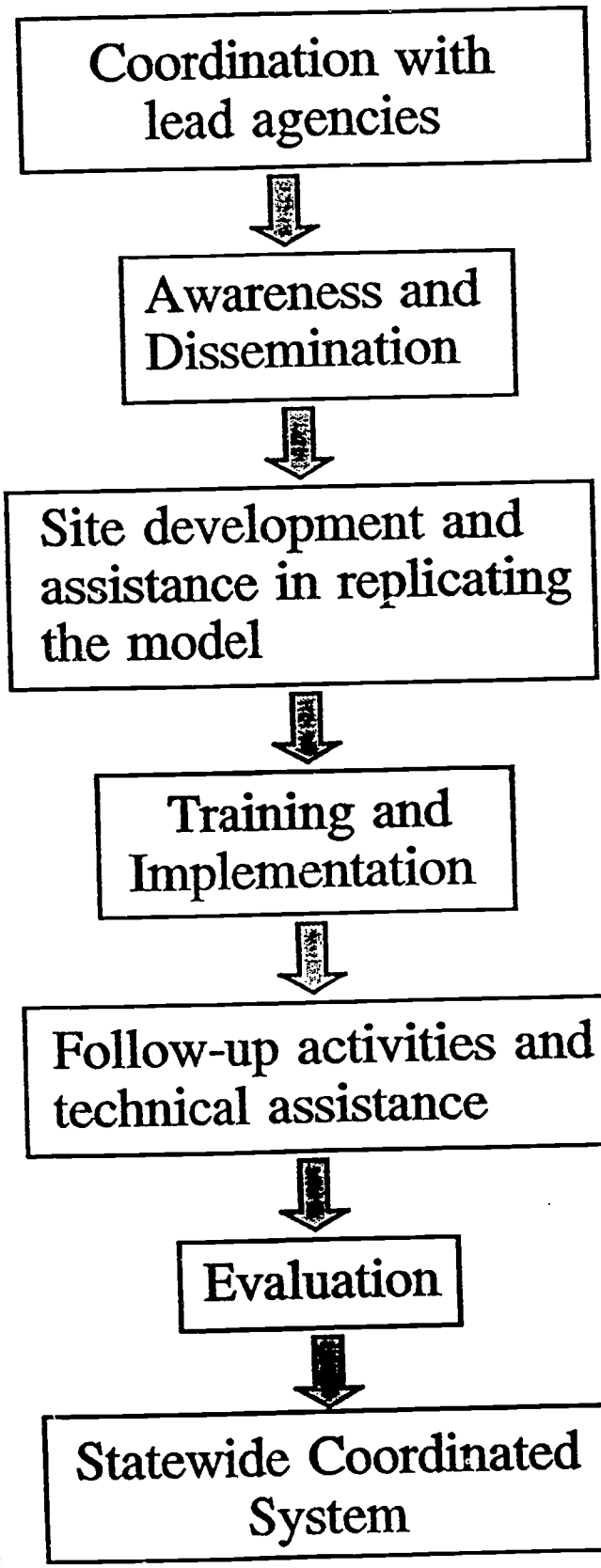
The above activities are described in further detail throughout Section C which reports on the accomplishments made in each of the objectives and components of the model. Figure 2 on the next page depicts the flow of outreach services to agencies in a sequential manner. However, some activities are ongoing and not specific to an adoption site. Please note that all services to adoption sites begin through coordination with lead agencies.

Following Figure 2 is Figure 3 which illustrates the replication process an adopting agency experiences, from primary awareness to full integration into a statewide system. Figure 2 shows how the activities and procedures described above are used to accomplish replication. INSITE has developed an Adoption Process Checklist which staff members use at important checkpoints to monitor this process.

Figure 2

INSITE Outreach Design

Sequential Services to New Adopting Agencies



Ongoing Services

- Product Development and Dissemination
- Awareness
- Evaluation of Outreach
- Technical Assistance
- Training

Figure 3

The Replication Process

Primary Awareness

1. Contact state and local agencies/individuals.
2. Respond to requests for information.
3. Distribute brochures.
4. Present at meetings.
5. Make preliminary determination of status, needs, and match with the Model.

Secondary Awareness

1. Involve all appropriate state and local decision makers.
2. Determine potential commitment of agencies.
3. Conduct awareness conference and / or awareness telephone conference.
4. Facilitate inter-agency linkage.

Selection & Site Development

1. State and local agencies write letter of request.
2. Outreach make criterion-based selection of replication agencies.
3. Outreach consult with agencies on program development and the administrative considerations of implementation.

Basic Training

1. Agencies and Outreach determine appropriate training participants and plan training.
2. Participants obtain materials.
3. Conduct basic training.

Implementation

1. State and local agencies develop service delivery system.
2. New parent advisors deliver services.
3. Agencies develop administrative and supportive components.
4. Agencies maintain inter-agency cooperation.

Follow-Up & Monitoring

1. Coordinate with state agency.
2. Address needs identified during post-training consultation.
3. Monitor implementation 6 and 12 months after training.
4. Conduct basic training of additional personnel.

Training of Trainers

1. Recruit potential locally certified trainers among newly trained parent advisors.
2. Train and certify qualified parent advisors as state / local trainers.
3. State / local trainers maintain high quality training of new personnel.

Technical Assistance

1. Disseminate latest information and materials to agencies / individuals.
2. Continue support to certified trainers.
3. Agencies and individuals participate in regional conferences.

Statewide Coordinated System

1. The Model is a part of the comprehensive statewide system for early childhood special education.
2. Outreach maintains contact with state lead agencies and replicating agencies / individuals.
3. New local agencies in state are referred to Outreach.

Repeat Replication Process

C. Final Report on Objectives and Activities of the Project Over the Three Year Grant Period

Objective #1: To create appropriate public, professional and agency awareness of the needs for home intervention services to infants, toddlers, and preschoolers with multidisability sensory impairments and their families through the INSITE Model.

INSITE promotes public and professional awareness by responding to all requests for information, by speaking at conferences, and by disseminating materials nationwide through its network of replication sites. This well developed awareness and dissemination program has the following components.

a. INSITE has developed an *awareness brochure* that is aimed at creating more interest in the Program. It has a self-addressed, tear-off panel on which areas of interest in more information can be marked. INSITE then responds with the requested information. INSITE also has a 15 minute awareness video that is also mailed out on loan as requested.

b. The *Parent Advisor Network* shares implementation information through regional conferences and local meetings. Over the years, the network of INSITE part-time and full-time parent advisors (direct service providers) has grown to over 550.

c. The *certified trainer network* shares information through newsletters and conferences as well as through Basic Training delivered by National Trainers and by the local training systems firmly established in many states.

d. *INSITE materials* that are produced through research and product development are announced in the *SKI*HI Institute Newsletter* which reaches over 1,200 people, 3 times a year. These products are made available to the field and to parents through a distribution company called Home Oriented Program Essentials, (HOPE). Through the efforts of HOPE, parents and professionals can access INSITE materials at a very modest cost.

e. Awareness and other Project INSITE materials are disseminated to the field directly by the project through the mail as well as at national, regional, and local conferences and awareness sessions.

f. Project staff have made presentations at various conferences about the INSITE program, materials, and data. The director presented a paper at Partners in Progress III meeting in Washington, DC in July, 1990 and at the Canadian Deaf Blind Conference in Winnipeg, Canada, in August, 1990. The assistant director presented at the National Diffusion Network conference in

Washington, DC, January, 1990, and at the Texas State Wide Conference for the Deaf in Houston, August, 1990. Several staff members made individual presentations on various INSITE related topics at the Western Regional Conference in Durango, CO, August 1-3, 1991 and at the North Central Regional Conference in Minneapolis, MN in August 1992. The assistant director published an article in the California Association of School Business Officials about the SKI*HI Institute. This publication is distributed throughout California to all school districts.

g. *Awareness Conferences* are conducted in three formats designed to help states evaluate and choose INSITE in light of state-defined goals for systemic changes: (1) An on-site awareness conference is provided for an agency or state to a selected audience including state agency personnel, State Facilitator, administrators, and other state or local decision-makers. These participants collaborate with the INSITE representative in determining local status and needs and how INSITE can become a part of the state's early intervention plan. (2) A teleconference is conducted with a pre-selected group of key individuals and prior to the conference, awareness materials are sent to these conferees. (3) INSITE has designed a new awareness option in which INSITE arranges a multi-state meeting with Part H and Section 619 coordinators, (services to age birth through 2 and 3 to 5, respectively) State Facilitators, and possibly Comprehensive System of Personnel Development (CSPD) coordinators. As the INSITE services are described, the attendees exchange information on goals, needs, and concerns.

During the course of this 3 year grant, 24 onsite awareness conferences were conducted for INSITE (AR, NC, NE NJ, IA, IN, OR, LA, OH, ND, MD, VA, NY, KS, DE, CA-4, WA, MA, MI, SD) nationwide.

Objective #2: To stimulate agencies to commit resources to the development and implementation of services to infants, toddlers, and preschoolers with multidisability sensory impairments and their families.

The project has developed an innovative statewide/region-wide awareness and dissemination conference process. The project is able to use the resources of the State Facilitator and the State Office of Education and/or Health Special Education Program to locate the appropriate target agencies and people to disseminate and facilitate the replication process. Through close work with the above facilitators, the project results in innovative activities with states, is able to understand the needs and goals of states in the area of early intervention, and to help meet those needs. Part H and 619 coordinators are essential to this new process in that all early intervention efforts *must* be coordinated with them. INSITE

requests that within the state, these coordinators form an advisory or steering committee to assist in selecting individuals to be trained, determine dates and locations for training, and provide the necessary single source coordination for INSITE implementation in their state. This statewide coordination is critical to successful implementation and long term systemic change, a major goal of Project INSITE.

The activities associated with site development and replication are listed in sequential order below:

a. Work with state lead agencies and local agencies to assess needs and the match with INSITE.

b. Locate potential replication sites. If there is sufficient interest in the INSITE Model, the state lead agency or agencies write a letter of request for outreach services. The state lead agencies then act as the coordinators between INSITE and local service agencies. Each local agency sends a letter of request indicating (1) the current status of services to children with multidisability sensory impairments and their families and the need for INSITE, (2) a commitment to using INSITE for at least a year after training, (3) an estimate of number of personnel to be trained, and (4) an estimate of the number of families and children who will receive INSITE services.

c. Select sites for replication. If the agency meets the criteria for adoption, adoption agreement is negotiated. The criteria for selection of adoption agencies are as follows:

1. Personnel have a positive attitude towards replication.
2. Personnel and financial resources will be committed to implement the program.
3. The agency is willing to share in or pay for outreach costs.
4. There is evidence of commitment to continue services after outreach assistance ceases.
5. There is a demonstrated need for the outreach services as evidenced by numbers of unserved or underserved infants, toddlers, and preschool age children who are multidisability or dual sensory impaired.
6. Agency personnel have made an official request for outreach services.
7. Agency personnel agree to provide equal access and treatment for all children who are members of groups that have traditionally been underserved, including minority, low-income, and rural families, and to provide culturally competent services in local areas.
8. An adoption agreement incorporating points 2, 3, and 4 has been or will be signed by a responsible administrator of the potential agency.

9. The adoption conforms to the state's plan for early intervention and preschool and related services and the state lead agency is aware of or coordinating the adoption activities.

d. Coordinate with and provide information to state lead agency and local agency administrators and supervisors for program development. When a new agency has made a commitment to replicating INSITE, the INSITE project works with the adopting agency's staff to ensure optimal development of the program. INSITE provides guidelines in development of the program, recruiting personnel, deciding who should attend training, and coordinating INSITE implementation with states' fulfillment of the IDEA.

The INSITE coordinator/trainer arrives one day prior to the training and meets with the local coordinator. During the series of two training sessions, the trainer/coordinator provides technical assistance to personnel as they prepare to adopt the model. Following the last training session the trainer/coordinator remains for an on-site technical assistance visit.

e. Provide materials for replicating agencies. Each replicating agency will obtain a basic set of materials necessary for INSITE service delivery for each parent advisor working with families. INSITE will determine the number of manuals and other materials which the agency will pay. The trainer/site coordinator works with the disseminator to be sure the manuals are delivered prior to training.

During the 3 years of this grant, adoptions or scheduled adoptions resulted from the awareness meetings in the following states: AR, NC, NE, IA, IN, OH, SD, KS, DE, MA, CA, and MI. In many states, there were several adoptions per state. Initial plans for INSITE training and implementation were then put into place for each of these states. Each state committed financial resources through the combined efforts of their lead agencies (i.e., Part H, 619, VI-C, NDN state facilitators) and the local adoption agencies.

Objective #3: To provide training to adoption agencies to enable personnel to implement INSITE curriculum and procedures in conjunction with their state plan to serve young children with disabilities and their families.

Typically, a trainer/coordinator and a co-trainer are selected by the INSITE Outreach staff to work with a state (or site). The trainer/coordinator conducts much of the pre-planning for this workshop by phone with the state contact person for INSITE. Once all preparations have been made and participants selected, the trainer/coordinator and a co-

trainer conduct the two on-site training sessions at the site for a total of six days, with the size of the workshop being limited to 25-30 participants for maximal training benefit.

Participants learn how to make optimal use of INSITE programming in order to plan a coordinated individualized program for a family. The trainers make use of the expertise of the participants in practice and presentations. They also assist local personnel in determining ways the model can be incorporated easily into their existing programs.

A variety of teaching methods and materials are used in the training workshops. These include video tapes, slides, overhead transparencies, handouts, demonstration, lecture, discussion, small and large group work, practice, role playing, chalkboard, and direct work from the manuals. The two trainers take turns in presenting.

A post-training conference meeting takes place immediately following the last training workshop. Evaluation of training is completed through evaluation at the end of the workshop and a six-month follow-up.

The trainees can obtain college credit for workshop participation through Utah State University's continuing education program. A brief description of workshop content follows:

OVERVIEW OF INSITE WORKSHOPS

Day One

- Family Focused Home Intervention - Principles and Practice
- Overview of the INSITE Model
- Who Is The Child With Multidisability Sensory Impairment?
- Role and Characteristics of the Parent Advisor
- Working with Families
- Family Focused Interview

Day Two

- Developmental Assessment of the Child: INSITE Checklist
- Planning, Reporting, and Getting Started
- Communication Program

Day Three

- Motor Development
- Understanding Posture and Movement Disorders
- Handling, Positioning and Adaptive Equipment
- Self-Care Needs, Feeding
- Planning for Second Workshop and Time with Local Supervisor

Day Four

Review
Participants share their INSITE experiences
Hearing Aid Program
Auditory Program
Cognition Program

Day Five

Anatomy, Function, and Disorders of the Eye
Visual Assessment and Working with Eye Doctors
Vision Program

Day Six

Application of the INSITE Model: Assessment, Goal Setting, and Program Planning with a Child and Family
Pulling It All Together
Data Collection
Where Do We Go From Here?

Over the 3 years of this grant, INSITE Outreach conducted basic training workshops for 442 new professionals in 12 states (1989-90 MN-33, FL-11, OK-8, OR-32, CT-32, KS-30; 1990-91 Lower MI-23, MA-21, MN-25, Southern CA-25, OK-25; 1991-92 N. CA-33, SC-20, OK-18, KS-20, PA#1-25, PA#2-25, SD-25, Upper MI-11). These professionals came from many different agencies within each of those states. It is estimated that these professionals began using the INSITE materials and training with a total of about 88 families of children with multidisability sensory impairment.

A representative summary of basic training evaluations can be found in Appendix B. Participants demonstrated initial understanding and competencies during training through practicum experiences and small group activities.

For a variety of reasons, a state may desire additional training in the following year or years. Therefore, INSITE works out a plan for continuation training with the local state agencies.

Objective #4: To assist agencies in implementation of the INSITE Model.

a. Once the steps described under objective two for site development and replication have taken place and the first basic training has been completed, project INSITE continues to work with the state and its agencies as needed and requested. Year two training for professionals from new agencies within a

state is provided. Consultation by phone and onsite visits by project staff may be made.

During the 3 years of the grant, the following consultation activities took place:

- An outreach staff member assisted a new Texas INSITE coordinator in onsite consultation and in a regional conference in Houston.

- An outreach staff member assisted a new Oklahoma INSITE coordinator in onsite consultation and in updating parent advisors on the newly revised INSITE manuals.

- Trainer/Coordinators made tentative needs assessments during exit conferences at the end of each training session. Monitoring of newly trained sites was provided and was an ongoing process with those sites requesting the service. Long term monitoring was also made available to sites as requested.

- In April 1991, the Director presented at the statewide parent advisor conference in Texas. Another staff member attended the Southeastern Regional Administrators Conference in April. The sharing and planning of this group results in the biannual Southeastern Regional SKI*HI/INSITE Conference, which benefits all programs in that region.

- In one of the continuing agencies which received training, Minnesota, recent changes in state organization were anticipated to have an impact on statewide networking of INSITE users. Some consultation was provided. In Massachusetts and Michigan, consultation was provided by trainers on-site, and extensive ongoing consultation was provided by telephone to the liaison persons. In both states, the lead trainer from the first training was assigned to the Year Two training, to provide continuity and support.

b. Local State Trainers. The continued integrity of the INSITE model depends in large part on maintaining the quality of the training delivered to new users of the model. INSITE has developed a systematized program for preparing, certifying, and updating trainers at the national and local levels. One of INSITE's main goals in any state is to facilitate the establishment of a fully operational INSITE state trainer system.

A prospective trainer must have experience in working as an INSITE parent advisor and approval of the employing adoption program. After meeting these and other requirements, the prospective trainer must successfully complete

about 15 hours of intensive training. The new trainer is then authorized to conduct INSITE training in her or his region or state. INSITE conducted yearly trainer's training workshops for local/state trainers during the 1989-92 grant period. Evaluation summaries are found in Appendix C.

The following states had local INSITE trainers trained throughout the outreach project. Those starred are states that added new trainers to a local trainer system that was already in place. The numbers of trainings that these local trainers conducted within each year is also indicated. Some of these new trainers assisted national INSITE trainers with a session in their state. These are bracketed trainings.

	# of New Local Trainers			# of INSITE trainings they conduct a year for the state			
State	1989-90	1990-91	1991-92	1989-90	1990-91	1991-92	
* MN	2				[1]	1	
FL	3				[1]	1	
* SC	1			1	1	1	
* GA	1			1	1	1	
NM	2					[1]	
	9			4	4	4	
* TX		1				[1]	
OK		2					
* MO		1		[1]	[1]	1	
* WV		1		1	1	1	
* TN		5		1	1	1	
AL		3			1	1	
		1				[1]	
MA		14				([1])	double count
* NM			1				
* UT			2	1	1	1	
MI			3			1	
* WV			1	[1]	[1]	(1)	double count
* FL			1			(1)	double count
			8				
				11 +	14 +	18 =	43 trainings

(double counts not included in totals)

Total of 31 new local trainers, now making a total of 50

43 trainings x 25 average attendance = 1,075 professionals trained with at least 2,000 children and families served.

INSITE publishes a trainers' newsletter, maintains a roster of certified trainers, and includes sessions for trainers at national and regional SKI*HI Institute conferences.

c. National Trainer System. After maintaining ongoing certification, a locally certified INSITE trainer may apply to become certified at the national level. With final approval by Project INSITE and his/her local program, a new national trainer can become fully certified and eligible to conduct training outside the local region or state. INSITE provides a training and orientation session to new national trainers. A new trainer is then teamed with an experienced trainer for at least one national workshop series.

INSITE monitors the performance of its trainers through workshop evaluations. All national basic Training and Trainer's Training workshops are evaluated by the participants with a standard evaluation tool which is analyzed and summarized following each workshop by the project evaluator and coordinator. Data from evaluations are discussed by the INSITE staff and valid suggestions are relayed to trainers and incorporated into subsequent workshops.

INSITE workshops continually receive above satisfactory participant evaluations. A team of two trainers conducts INSITE training. The trainers are selected on the basis of schedule availability, individual strengths, and location. Every 2 to 3 years, INSITE attempts to bring all national trainers together for essential update and re-orientation. This was done in November of 1992 when all 10 of the national INSITE trainers were brought in to the project head quarters in Logan, Utah for a 3-day weekend session. Three of these were new trainers.

d. Demonstration Sites. INSITE considers each site with a certified National INSITE Trainer a demonstration site. INSITE will consider other sites which are committed to using INSITE for the distinction of being a demonstration site.

Objective #5: To evaluate the effect of the INSITE Model on child and parent progress and the effectiveness of the outreach process.

INSITE Outreach collects information on results of the Outreach process and on child and family progress in INSITE programming. An evaluator analyzes and interprets the information and evaluates the data collection process itself on an ongoing basis throughout the grant period. In this way, ongoing adjustment and improvement is possible. Evaluation results are reported to the field and to the U.S. Department of Education.

The outreach efforts are also evaluated continually to meet the needs of the audience it serves. These audiences include the statewide Part H and Section 619 coordinators, the State Facilitators, the direct service personnel trained, and the agencies they represent, and the children and families served by Project INSITE. Direct and indirect evaluation methods are employed to evaluate the process.

The Project maintains files of all adoption sites and a listing of adoptors, with addresses, contact person, and telephone. Every year, INSITE mails a simple survey form to all replication sites to determine current status of implementation and to update/correct address, telephone number and name of contact person. The form is on a self-addressed,

postage-paid postcard. Sites are asked to complete and return the form. Records and lists are then updated. Through this maintenance of site records come future local trainers, future site affiliations for mutual benefit, and future opportunities to gain child and parent data.

INSITE collects demographic and child/parent progress data from INSITE agencies across the country. Agency personnel are trained in assessment and data collection and entry. INSITE provides a demographic and child/parent progress data form for recording. The agencies obtain yearly pre- and post-treatment profiles on the Callier-Azusa Scale showing child progress. The data are sent to the SKI*HI Institute Data Center, where they are analyzed. This databank provides valuable information to replicating agencies which is useful for program evaluation, funding continuation, and program improvement. It is also an excellent source of demographic information on infants, toddlers,and preschoolers with multidisability sensory impairments, and is a potential data base for future research. INSITE staff produce an annual National INSITE Data Report based on these data. Significant results of data analysis are reported in Appendix D as well as in Section VIII.

Monitoring is a means by which INSITE determines the implementation status of the adopting agency or individual. Monitoring is conducted by correspondence, questionnaire, and telephone consultation. Information obtained through monitoring serves two important purposes: (a) it gives an indication of needs the agency or individual has for refinement of its implementation and how closely it is able to adhere to the model, and (b) it indicates the effectiveness of outreach training and INSITE technical assistance to date.

Objective #6: To develop instructional, curricular, and training materials for use with parents in the home and in training personnel in implementing the INSITE model.

Project INSITE at the SKI*HI Institute has a product development division and a national network of sites for field testing new curriculum programs and materials. The project follows a procedure established at the SKI*HI Institute, which begins with recognizing a need in the field. Based on need, the product is conceived and money is requested in the next budget. A prototype of the materials is developed and tested throughout the INSITE network. Revisions are made and a final master is produced. The product is then distributed in the INSITE network. This process was used throughout the three years of the project.

Based on need indicated by INSITE users, project resources helped to develop the products listed below during the 1989-92 grant period.

1. Finished the revision of the INSITE Resource Manual (600 pages in 2 volumes)
2. Update of Multimedia Training Package - with guidesheets, transparencies, and new videoclips to go with newly revised INSITE Manual
3. Video tape and workbook: Family Focused Interview
4. INSITE Topic Summary and Challenge Sheets
5. Monograph: Working with Families of Young Children with Special Health Care Needs (150 pages).
6. Resource Manual: Family Centered Intervention for Infants, Toddlers, and Preschoolers who are Visually Impaired (1,000 pages in two volumes)
7. Parent Resource Notebook
8. Revised INSITE Awareness brochure and updated other awareness materials

Items 1-4 and 8 were discussed in the Interim Performance Reports for Years One and Two. See Appendix E for title pages and contents for items 5, 6, and 7.

New training guidelines, handouts and transparencies were developed to go with the revised INSITE curriculum manual in January, 1990. An update workshop for national trainers took place in Logan that same month. Trainers received the new training package plus new trainer guidelines and a review of Institute products, projects, and procedures. In addition, the new training package was disseminated to states that had local trainer systems in place. Project staff gave onsite assistance to 5 of these states (TX, UT, GA, TN, OK) in updating parent advisors and/or local trainers on the new manual and training package.

Each year, INSITE staff looks critically at the training package and adds, improves, or replaces sections as needed to meet training demands.

All instructional, curricular and training materials developed by INSITE are announced in the newsletter and made available to the field and to parents through a distribution company called Home Oriented Program Essentials (HOPE) at a modest cost. Some of the materials are disseminated to the field directly by the project.

Objective #7: To assist states in developing full, coordinated services for families of infants, toddlers, and preschoolers with multidisability sensory impairments to implement Public Law 99-457.

This goal has been met through a variety of activities. They are described below.

a. *Pre-training* is conducted through telephone consultation and an on-site pre-training planning meeting by the INSITE trainer/coordinator. A *post-training* conference meeting takes place immediately following the last training workshop. These took place for each of the national workshops listed in objective three.

b. *Monitoring* is a means by which INSITE Outreach can help an agency determine its implementation status. Information obtained through monitoring serves two important purposes: (a) it gives an indication of needs the agency has for refinement of the implementation, and (b) it provides one means of assessing the effectiveness of outreach training and assistance to date.

About 6 months after the completion of training, the INSITE trainer/coordinator writes a letter to the administrator offering the monitoring service. If the administrator chooses to participate, INSITE staff telephones the administrator or supervisor and one or more parent advisors, using a questionnaire supplied ahead of time. The trainer/coordinator completes the questionnaire and makes recommendations. Copies go to the administrator and to the INSITE file.

If assistance from INSITE Outreach is part of the monitoring recommendation, INSITE staff provides this assistance. One year following basic training, the trainer/coordinator makes a second monitoring contact to the administrator and parent advisor(s), using the same process outlined. Periodic contacts are also made with the state lead agency by letter and telephone.

c. Every year, INSITE mails a *simple survey form to all replication sites* to determine current status of implementation and to update/correct address, telephone number and name of contact person. The form is on a self-addressed, postage-paid postcard. Sites are asked to complete and return the form. Records and lists are then updated. INSITE Outreach maintains files on all adoption agencies including adoption agreements, correspondence, training, and monitoring records.

d. A national survey concerning the type of technical assistance desired by sites was conducted in Spring and Summer of 1991. The number one item chosen was *regional conferences*. Therefore, INSITE Outreach made it a top priority to offer and support regional conferences for INSITE programs across the country.

The SKI*HI Institute has been very successful in germinating regional sharing and networking by conducting regional conferences. In 1986, the Institute conducted a Southeast Regional Conference in Birmingham, Alabama. Since then, the Southeastern programs have continued to hold a conference every other year. The responsibility for planning and hosting is rotated from state to

state. This conference has helped to strengthen those programs immensely. Over 300 participate at each bi-annual conference.

In 1991, the SKI*HI Institute hosted a four state Western Regional Conference in Durango, Colorado. It was attended by 127 professionals. This group is now planning on their own their second annual conference in Durango, Colorado in August of 1993. Approximately one-half of the conference participants are trained in and use INSITE programming.

During the Summer of 1992, the SKI*HI Institute sponsored a North Central Regional Conference in Minneapolis-St. Paul. More than 75 parent advisors attended from a 10 state area. At this conference, committees were formed to plan a West North Central and an East North Central Regional Conference in summer of 1994. It should be noted that these conference/workshops provide the only forum directed specifically to INSITE parent advisors. Of interest is that both the North Central and Western Regional conferences received support from some of the State Facilitators in these areas.

INSITE continues to provide support to these regional efforts by making staff available to answer questions from regional planning committees and by sharing guidelines it has developed for regional conference planning. In addition, INSITE provides information for regional conference sessions planned to update participants on new developments in INSITE or to update local INSITE trainers in the regional training workshops.

e. *Support of the national trainer network* is another major technical assistance service. By equipping and updating the trainers, INSITE is ensuring that quality training and preparation of service providers will continue to take place. Local as well as national trainers benefit, and thus the capacity of state and local programs to implement the model is enhanced.

f. Finally, INSITE sends out *newsletters, conference announcements, new-product announcements*, and other information to keep adoptors current on INSITE .

g. INSITE Outreach collects demographic and child/parent progress data from INSITE agencies across the country. Replication agency personnel are trained in assessment and data collection and entry. The project provides a demographic and child/parent progress data form. The agencies obtain yearly pre- and post-treatment profiles on the Callier-Azusa scale showing child progress. The data are sent to the SKI*HI Institute Data Center, where they are analyzed. This data bank provides valuable information to replicating agencies which is useful for program evaluation, funding continuation, and program improvement. It is also an excellent source of demographic information on infants, toddlers, and preschoolers with multidisability sensory impairments, and is a potential data base for future research.

VII. METHODOLOGICAL/LOGISTICAL CHALLENGES AND HOW THEY WERE RESOLVED

The project faced challenges in two main areas during the grant period: (a) a change in the needs of states, agencies, and training participants and (b) a need to maintain closer contact with the agencies and individuals who had received training and assistance in past years. These challenges, and the response by INSITE Outreach, are described below.

Challenge #1: The Change in Outreach Needs

When INSITE was first providing outreach training and assistance, the recipient agencies and individuals were those specifically serving children with sensory impairments or multiple disabilities in special programs. Since these agency personnel for the most part had a specialized educational background, training, and work experience with this population, INSITE training had been designed to build upon this existing knowledge and expertise. Traditionally, it consisted of two 3-day workshops, with 6 to 8 weeks in between.

With the advent of P.L. 99-457 and P.L. 102-119, children with low-incidence disabilities such as multidisability sensory impairments are now also beginning to be served within early intervention/early childhood programs for all infants, toddlers, and preschoolers with disabilities. In addition, states are expected to maintain more coordinated statewide services to children in the birth to 5 age range. The changes in service setting and state needs have opened a new arena and demand for INSITE Outreach services.

When the INSITE service model is delivered through local school districts and early intervention agencies, the personnel who deliver it may not have been trained to serve children with low-incidence disabilities such as multidisability sensory impairment. Instead, they have generally received cross-categorical training, and may never have worked with a child with sensory impairment. The need for training to help prepare these personnel to effectively serve children with specialized needs has become acute.

On the other hand, in other locations or training situations, the participants may all be highly experienced and trained in specialized areas, but in different disabilities. There may be three or four subgroups in the workshop each needing a different set of information and skills.

Another problem encountered in facilitating the training is that often only one or two persons from an entire agency serve children with multiple disabilities and sensory impairment. In addition, most early interventionists who are working with these children and need the specific training offered through INSITE are generally scattered through several agencies over large geographic areas. Except for the larger metropolitan areas, there are usually only a few children with multidisability sensory impairments in each local early childhood or parent-infant program. Therefore, INSITE cannot expect to have all the participants in a workshop coming from the same agency to have training needs in common.

During the three years of this Outreach grant period, Project INSITE Outreach addressed these concerns by developing an awareness and training format designed to be flexible in meeting a variety of needs. In responding to today's demand for coordinated statewide services and for systemic change, INSITE Outreach conducts all awareness, dissemination, planning, training, and technical assistance through close cooperation with state education coordinators, Part H and Section 619 coordinators, and other lead agencies for services to children ages birth to 5 and their families.

In the new training format, the first 3-day workshop is devoted to an overview of the INSITE model and resource manual, and a demonstration of how to assess a child initially for planning. Participants choose from a selection of assignments one that they will complete between workshops. They also choose which of the aspects of the model they would like to have covered in depth at the second workshop. There is a possibility of holding two concurrent sessions at the second workshop if the group is divided on needs. There is also a possibility that a full three days will not be used for the second workshop, if the participants do not feel a need for in-depth coverage of many of the topics. Also, trainers make use of the specialized expertise in each training group by inviting participants to assist in presentation in their specialty areas. See Appendix F for the new INSITE training format.

This new approach to training and coordination has several benefits:

1. INSITE training may be adjusted and tuned in a great number of ways to meet the needs of each group of trainees. The expertise and knowledge of participants is acknowledged and utilized. Participants become more aware of the resources they have in their own local area.

2. The between-workshop assignment gives participants a chance to become involved and get hands-on experience with an aspect in INSITE. This contributes to a deeper understanding by the end of the training period.

3. Greater involvement by state agencies can help fill states' needs for a more coordinated approach to early intervention. INSITE provides a crucial piece in the states' provision of services to the birth-to-5 age group in fulfillment of requirements under Parts H and B of the Individuals with Disabilities Education Act.

Project INSITE Outreach offers critical training features to school districts and other agencies serving infants, toddlers, and preschoolers with multidisability sensory impairments. These training features include how to work with parents and other caregivers in the home and other settings outside the school. The training includes working with infants, toddlers, and preschoolers and the unique needs associated with their disabilities. These elements included in the training are necessary to ensure optimal state and national programming and to ensure that Goal #1 of America 2000 is achieved. This goal states that *all* children will enter school ready to learn. It is imperative that children with multidisability sensory impairments receive the programming and materials offered through INSITE Outreach, for these children are part of the realization of this goal.

Challenge #2: The Need to Maintain Closer Contact with Previously-Trained Agencies and Individuals

INSITE Outreach has conducted a survey of sites every year to update records and determine the yearly impact of INSITE. Outreach staff knew, however, that more information was needed about INSITE user agencies and individuals if appropriate technical assistance was to be delivered.

Therefore, during the first year and one-half of the Outreach project, a comprehensive survey of replication sites was conducted nationwide. There were two purposes: one was to determine the status of programming in these agencies. The second purpose was to determine what the agencies perceived as their greatest needs for ongoing technical assistance from the Outreach project.

The response indicated that the agencies were continuing to use INSITE programming and materials and were reading and using the newsletters and other mailings. They wanted to continue receiving information and materials, and in addition, they wanted more

opportunities for update training as well as certification of experienced parent advisors as trainers in the local areas.

In the area of need for and interest in technical assistance, the most frequently requested categories on the survey were (1) regional conferences and (2) administrators' sessions at regional conferences.

During the remainder of the grant period, INSITE Outreach joined with SKI*HI Outreach, another EEPCD project, to sponsor two regional conferences in parts of the country where none had been held. The first was the Western Regional Conference in Durango, Colorado, July 31 - August 3, 1991 (reported in the Year Two Interim Performance Report), and the second was the North Central Regional Conference in St. Paul, Minnesota, July 30 - August 1, 1992 (reported in this Final Report, page 25).

The goals were (1) to bring SKI*HI and INSITE users together to share and gain new knowledge, (2) to establish closer contact between Outreach Project and these users, and (3) to encourage these regions to continue holding periodic regional conferences on their own.

All of these goals were accomplished. The western states are completing plans for a Western Regional Conference in Durango, August 4-6, 1993. The north central states have divided into a western and an eastern group and each is planning a conference for Summer, 1994. INSITE Outreach is contributing staff consultative time to these planning groups and is providing financial support. In addition, the SKI*HI Institute is committed to sending one or more staff members to each conference.

Each year during the grant period, INSITE also assisted the southeast regional program administrators, who meet yearly and also hold a regional conference every other year. This is a strong and productive conference which has been operating since 1984.

Evaluations and comments from all the regions continue to indicate that regional conferences are an excellent way to provide needed assistance and information as well as keep channels of communication open among INSITE users and between users and the SKI*HI Institute.

VIII. EVALUATION FINDINGS

A. Impact on Children and Families

Project INSITE was approved by the Program Effectiveness Panel of the National Diffusion Network in March 1989 as having provided "convincing evidence of the effectiveness of your program." This approval was based on data collected on children and families served by INSITE in 10 states from 1982 to 1988. Data from the validation study are summarized below. Data from the most recently reported data year, 1991-92, are also summarized below. These data show that developmental claims during the first six years of INSITE still hold true. The full 1991-92 Annual Data Report is in Appendix D.

The Callier-Azusa Scale is administered to INSITE children annually on a pre/post basis. This test is designed for children at lower developmental levels (e.g., children with deaf-blindness or multiple disabilities). The Callier-Azusa Scale is composed of 18 subscales which are organized according to the following five developmental areas: motor, perception, daily living, cognition/communication/language, and socialization. In 87% of actual versus predicted post-test score comparisons from 1982-1988, INSITE children scored higher at post-test time than what was predicted. Average annual post-test scores reveal that INSITE children score higher in all but one developmental area than what would be expected due to maturation alone. Test scores were transformed to Intervention Efficiency Indices (Bagnato and Neisworth, 1980), and compared to pre-test developmental rates. These transformations yielded Proportional Change Indices (PCIs) which compared rates of development during intervention to rates of development at pre-test.

PCIs for INSITE children from 1982-1988 were computed: all PCIs (100%) showed accelerated rates of development for the children during their INSITE programming.

INSITE programming continues to yield these positive results. In the most recently reported data year, 1991-92, Callier-Azusa scores from INSITE children in 11 replication sites were gathered and analyzed. In all but one of the five developmental areas tested by the Callier-Azusa Scale, the actual mean post-treatment values not only showed improvement over pre-treatment values, but exceeded the predicted values. These data indicate that

INSITE children continue to score higher at post-test time than would be expected due to maturation alone.

To test rate of growth during intervention, PCIs were derived from the 1991-92 Callier-Azusa scores. In all developmental areas, the mean PCIs were above 1.0, ranging from 1.3 for daily living to 2.4 for cognition, communication, and language. Thus, it can be stated that the average INSITE child shows accelerated growth during INSITE programming in all developmental areas.

For the 1989 validation study, in order to determine how many INSITE "graduates" remain in the home versus "graduates" who were institutionalized, a survey was sent to INSITE program supervisors to determine current placement of INSITE graduates. Surveys from 10 states were received which included information on 853 graduates. The results showed that 99.7% of the INSITE graduates in this study were currently living in their homes while 0.3% were institutionalized. Of the 850 children living in their homes, all but 1.3% were receiving other services such as school or center-based services.

In parent skill acquisition during the years of 1986 to 1988, the typical INSITE parent acquired many new skills during an average time interval of 7.8 months. For example, parents learned an average of 14 new communication skills, which represents almost half of the total number of communication skills in the INSITE Program. All gains in skills acquisition in all curricular areas were statistically significant at the .05 level.

Seventy-one parents from eight states completed a parent perception scale. INSITE parents perceived significant improvement in their abilities to manage their child's disabilities and promote their child's development as a result of their participation in INSITE. Hundreds of solicited and unsolicited letters from INSITE parents throughout the country further support the claim that INSITE programming is extremely important to them in meeting their child's needs and their own needs, especially in the area of emotional adjustment.

INSITE data demonstrate the effectiveness of the procedures and materials used to intervene and provide meaningful assistance to parents and families of children with MDSI. As children begin to show progress in attaining higher developmental milestones, parents are encouraged and fortified in their ability to parent their child. This confidence is magnified and is manifested in the parents becoming truly effective advocates for their children who are MDSI.

The quality of the staff and the services they provide are best evaluated by the people they serve. INSITE asked the agencies who have received outreach service in the past few years if they would write a letter evaluating the services they received. INSITE received an immediate response. All the letters give support to INSITE, emphasizing the positive impact of the outreach services on their program. Representative statements from other replication agencies are shown below:

> The benefits of having a nationally recognized program that supports home visitation rather than site based intervention adds needed credibility to our program. I have worked in both kinds of programs. It has been my experience that home programming supports the entire family in developing a positive and meaningful relationship with their handicapped infant. Another benefit is that home programming provides better inter-agency collaboration.
>
> Debra Lively
> Parent Resource Center, Michigan

> Last summer our staff attended an overview session of the INSITE program. Since then, they have been able to provide overviews of the program to interested educational agencies. The positive side to that is the ultimate presentation of two trainings in the state. Sessions were held in Northern California in January and April of 1992. Staff attended and assisted in the trainings and were most appreciative of the expertise the national trainers brought to our area. Southern California sessions were held in January and March. Again, the input from your trainers was invaluable. Interest for these workshops was so great that each had waiting lists of individuals wanting to attend. It is for this reason and because we value the information developed by SKI*HI Institute, that we support your program.
>
> Steve Johnson
> California State Department of Education

> I am writing in support of the SKI*HI and INSITE intervention models. As the Part H Coordinator for Ohio, I am looking forward to your help in using these models as part of our comprehensive system of personnel development. These models will provide specific training to personnel from early intervention programs throughout Ohio.
>
> Cindy Oser
> Department of Health, Ohio

> It is to your credit that the model incorporates the components of P.L. 99-457 and its reauthorization (now known as P.L. 102-119) such as service provision in the most natural setting; a family-centered approach and implementation; a

multidisciplinary team; an IFSP process and an assurance of confidentiality, to name a few.

Audrey Witzman
Illinois State Board of Education

Since 1981, Project INSITE has provided services in the homes of deaf-blind and blind infants in rural areas of Utah. It has been an extremely successful program, and the parents involved have witnessed remarkable progress in the development of their severely handicapped children.

David L. West
Utah Schools for the Deaf and the Blind

B. Impact of Training Sessions

1. Evaluations of Awareness Conferences

INSITE Awareness presenters collect evaluations of each awareness conference. A representative summary of evaluations for these conferences from 1989-90 and 1990-91 can be found in the interim reports for those two grant years. A representative summary for 1991-92 can be found in Appendix G of this document.

2. Evaluation of INSITE Basic Training

INSITE collects participant evaluations of every training session. Percentages of participants giving each response are indicated. A representative summary of evaluations for these conferences from 1989-90 and 1990-91 can be found in the interim reports for those two grant years. A representative summary for 1991-92 can be found in Appendix B of this document. For items that do not add up to 100 percent, not all of the participants responded.

3. Evaluation of Workshop for New Local Trainers

INSITE conducts a local trainers workshop each year to prepare and certify experienced parent advisors to become trainers for their programs. A representative summary of evaluation for these workshops from 1989-90 and 1990-91 can be found in the interim reports for those two grant years. A representative summary for 1991-1992 can be found in Appendix C of this document.

4. Summary of Evaluations for Technical Assistance and Regional Workshops

In the Summer of 1991, Project INSITE assisted in planning, funding, and conducting the first Western Regional Conference for users of the SKI*HI and INSITE Models in this

region of the country involving 127 participants from 4 statewide programs. A summary of participant evaluations is in the interim report for 1990-91.

In the Summer of 1992, Project INSITE assisted in planning, funding, and conducting the first North Central Regional Conference for users of SKI*HI and INSITE Models in that region of the country, involving 85 participants from 9 states. A summary of participant evaluations can be found in Appendix H.

IV. PROJECT IMPACT

A. State-of-the-Art Materials

The INSITE Project has developed and produced a wide variety of materials for use in home intervention with infants, toddlers, and preschoolers who are multidisabled sensory impaired and their families. Project INSITE provides instructional, management, testing and training materials. Basic materials are provided to new adoption sites. These materials are essential to successful early home base programming for children and are developed, published, and distributed only by INSITE Outreach in Logan, Utah.

To assist the reader in understanding the evolution of Project INSITE in maintaining a state-of-the art level of proficiency, a chronology of innovations, developments, and revisions of the INSITE program is presented.

1981-84	Model Demonstration program. Development and printing of curriculum manual.
1984-85	Expansion and update of INSITE Vision Program. Publication of a manual, "Developing Sign Communication with the Multihandicapped Sensory Impaired Child." Development of a Family Needs Assessment and Readiness Program.
1986-87	Addition of Communication, Vision, and Auditory Subscales to INSITE Developmental Checklist. Completion of a comprehensive training package.
1987-88	Development and printing of Home-Based Programming for Families of Handicapped Infants and Young Children, a comprehensive manual on home intervention principles and procedures in family dynamics, parent support and family goal setting. Incorporation of P.L. 99-457 principles into the INSITE model. Development and publication of best practices handbook, The Management of Home-Based Programs for

Infant, Toddler, and Preschool-Aged Handicapped Children. Comprehensive revision and update of INSITE curriculum manual. Extensive revision and update of training guidelines and media to train parent advisors on the revised curriculum.

1989-90 Production of new training videotapes. Writing of a new resource manual, The INSITE Model: Resources for Family Centered Intervention for Infants, Toddlers, and Preschoolers who are Visually Impaired.

1990-91 Development and production of video tape set and accompanying workbook, "The Family-Focused Interview." Beginning use of new video taped coactive sign system for children with deaf-blindness developed by the TIPS Project at the SKI*HI Institute. Writing and publishing of a parent information resource, "INSITE Topic Summary and Challenge Sheets."

1991-92 Writing of a monograph, "Working with Families of Young Children with Special Health Care Needs." Completion of a new resource manual for professionals working with preschoolers who are blind and low vision. Inauguration of new inservice training program for teachers who expect to have children with visual impairments in their classrooms or case loads. Participation in new project for technical assistance to programs serving individuals with deaf-blindness in Utah.

1992-93 Writing of a new Parent Resource Book containing useful information plus sections to hold important papers such as medical reports and test results. Development of a new INSITE training format which allows for more participant/agency choice in content. Addition of new video tapes to training package. Participation in a new training program for Interveners (child service providers for young children who are deaf-blind). Participation in writing a new manual for paraprofessionals, parents, other caregivers and professionals, "A Resource Manual for Understanding and Interacting with Infants, Toddlers, and Preschool Age Children with Deaf-Blindness."

The INSITE model is a growing, changing model that is concerned with the complete child and family. A constant effort is maintained to ensure that the model represents the latest research and best practice in the field.

In addition to the publications listed above, project INSITE contributes to the SKI*HI Institute newsletter that goes out to INSITE and SKI*HI parent advisors, administration and programs throughout the country three times a year.

INSITE also contributes to the biannual "Trainer's Tidings" that is mailed to all local and national INSITE and SKI*HI trainers across the country.

B. Summary of Outreach Activities

INSITE also assists with the annual survey that goes to replication sites and programs around the country. That information, along with data kept at the project office provide the information needed for the yearly INSITE fact sheets found on the next few pages. These reflect the impact INSITE has had over the last three years.

Summary of Impact of INSITE Outreach Activities 1989-92

	National	Local
Dissemination Process to State Agencies	24	NA
Basic training workshops for new adopting sites Basic training workshops for continuing adoption sites	11 8	43
Attendance at basic training workshops	442	1,075
Previously unserved or underserved children/families expected to be served by INSITE	884	2,000
Consultative assistance to sites	20	NA
Trainer's workshops to certify new local trainers	3	NA
Number of new local trainers certified and receiving training materials	31	NA
Number of regional conferences	3	
Number of attendees at regional conferences	327	NA
National Trainers' Meetings for update, retraining, and revision of training packages	3	NA
Number of new national trainers certified	3	NA

X. FUTURE ACTIVITIES

A. Training, Impact on Programs and Families, Assistance to Sites

Project INSITE Outreach wrote a grant application for a new 3 year period (1992-95) through OSEP-EEPCD and has been funded to continue INSITE Outreach activities with new states and programs around the country. Because of the great need for INSITE training and

materials, application for a new INSITE grant through the National Diffusion Network has just been completed and mailed to the NDN office in Washington, D.C. If that grant is funded, it will enable INSITE to work with even more new states over the next few years as well as to develop new training and curricular materials.

Through both three year grants, the following impact would be expected.

1. At least 7 national trainings would take place each year for a total of 21 over the 3 year grant periods resulting in a total of 525 professionals trained. Each of these is projected to serve at least two children with the INSITE model and curriculum impacting 1,050 children and their families.

2. INSITE will continue to grow and expand in most of the 27 states where training has taken place. The projects impact will begin to develop in at least 10 new states.

3. Around twenty new local trainers will be trained through three yearly local trainer workshops. A couple of new national trainers will be added to the project.

4. Four regional INSITE/SKI*HI workshops will take place.

5. The new professional organization for parent advisors, the American Association for Home-Based Early Interventionists (AAHBEI) will continue to grow and conduct its first national conference.

6. Technical assistance can continue to be provided to sites across the nation.

B. New Products and Materials

Through these new grants, the following materials would be developed for INSITE users in the field.

1. Videotape for training on functional vision assessment.

2. Updated training packages and videoclips.

3. Three new information sections for the INSITE Parent Resource Book.

4. Spanish translation of Topic Survey Challenge Sheets.

5. Spanish translation of Parent Resource Book.

6. Update INSITE video overview.

7. Three yearly newsletters to go out to over 2,000 professionals.

8. Two yearly "Trainers' Tidings" to go out to all national and local trainers.

9. Manual to help trainers integrate training on the new Tactile Sign System developed by SKI*HI Institute technology grants into the basic training workshops.

10. A new video case study of a young MDSI child for use in training.

11. Sections to go into a new manual for parent advisors on home based programming.

XI. ASSURANCE STATEMENT

INSITE confirms that the full text of this report is being sent to ERIC and that copies of the title page and abstract/executive summary have been sent to the other addresses on the attached sheet.

Appendix A

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Appendix B

Summary of Basic Training Evaluations

1991 - 1992

INSITE BASIC TRAINING WORKSHOP EVALUATION SUMMARY

SITES: Mission Viejo, Sacramento, Oklahoma, Michigan, Kansas
DATE: 1991-1992
NUMBER OF RESPONDENTS:
WORKSHOP #1 - 111 WORKSHOP #2 - 81

QUESTION	PERCENTAGES WORKSHOP #1	WORKSHOP #2
1. Compared to other programs I have attended, this workshop is in the:		
Top 10%	56%	70%
Top 25%	24%	20%
Middle 30%	12%	9%
Bottom 25%	4%	0%
Bottom 10%	2%	0%
No Response	2%	1%
2. The stated workshop objectives corresponded closely to what has actually been done:		
Strongly Agree	54%	67%
Agree	37%	33%
Neutral	3%	0%
Disagree	5%	0%
Strongly Disagree	1%	0%
No Response	0%	0%
3. Compared to the instructional staff of other programs, how would you rate the instructional staff of this program?		
Top 10%	50%	61%
Top 25%	30%	29%
Middle 30%	13%	4%
Bottom 25%	3%	1%
Bottom 10%	3%	0%
No Response	1%	5%
4. Did this program generally meet your expectations?		
Yes	88%	100%
No	12%	0%
5. Would you recommend this program to a colleague?		
Yes	90%	100%
No	8%	0%
No Response	2%	0%

QUESTION	PERCENTAGES WORKSHOP #1	WORKSHOP #2
6. Did you have enough information about this program before you arrived?		
Yes	63%	84%
No	35%	16%
No Response	2%	0%
7. If I had a choice, I would/would not take a program from this instructor again because:		
Would	88%	94%
Would Not	9%	1%
No Response	3%	5%
8. I feel adequately prepared to apply the subjects covered:		
Strongly Agree	27%	28%
Agree	59%	66%
Neutral	8%	6%
Disagree	6%	0%
Strongly Disagree	0%	0%
No Response	0%	0%

Appendix C

Summary of Local Training Workshop Evaluations

1992

INSITE TRAINER'S TRAINING EVALUATION

SITE: SKI*HI Institute, Logan, Utah
DATE: June 11-13, 1992
TRAINER(S): Bess Morgan
PARTICIPANTS:

QUESTION	RAW SCORE	PERCENTAGE
1. Compared to other programs I have attended, this workshop is in the:		
Top 10%	6	86%
Top 25%	1	14%
Middle 30%		0%
Bottom 25%		0%
Bottom 10%		0%
2. The stated workshop objectives corresponded closely to what has actually been done:		
Strongly Agree	7	100%
Agree		0%
Disagree		0%
Strongly Disagree		0%
Don't Know		0%
3. Compared to the instructional staff of other programs, how would you rate the instructional staff of this program?		
Top 10%	6	86%
Top 25%	1	14%
Middle 30%		0%
Bottom 25%		0%
Bottom 10%		0%
4. Did this program generally meet your expectations?		
Yes	7	100%
No		0%
5. Would you recommend this program to a colleague?		
Yes	7	100%
No		0%
6. Did you have enough information about this program before you arrived?		
Yes	7	100%
No		0%

7. **In which area did you require additional information?**

(1) Registration (2) Lodging/Food Service
(3) Parking (4) Location/Facility
(5) Other 7 No Response

8. **If I had a choice, I would/would not take a program from this instructor again because:**

Would	7	100%
Would Not		0%

Comments:

- Organized
- Excellent facilitator, open to group
- Valuable information presented, program well paced

9. **I feel adequately prepared to apply the subjects covered:**

Strongly Agree	3	43%
Agree	4	57%
Disagree	%	
Strongly Disagree	%	
Don't Know	%	

Comments:

- I'm scared! Are we ever fully prepared?
- ...with a little help from my friends!

10. **What were the best aspects about this workshop?**

- The information
- The people
- The super social events
- The broad range of knowledge of presenters and participants
- Interaction between participants
- Ideas for motivators
- Discussion and practical application
- Kindness
- Location
- Materials

11. **Describe the most valuable ideas that you received from attending this workshop:**

- Organization
- Materials
- Appreciated overview on what worked and didn't work based on experience

Valuable Ideas - Cont.

- Learning how to teach and motivate adults
- Sharing responsibilities
- I know I have the full support of the INSITE team

- Exchange of ideas, sharing
- The correct way to teach the INSITE Model, specific information on facilitating
- Information in the manual to assist in using and training for INSITE

12. **How could this program be improved if it is offered again?**

- Make it longer
- It was excellent!!

Appendix D

INSITE Data Report, 1991-92

INSITE 1991-92 NATIONAL DATA REPORT

SKI*HI INSTITUTE
Department of Communicative Disorders
Utah State University
Logan, Utah 84322-1900

January 15, 1993

INSITE SITES THAT SUBMITTED DATA 1991-1992

GEO Atlanta Area School for the Deaf

NXO New Mexico School for the Deaf Preschool

TAC Dallas RDSPD

TBR Arlington RDSPD

TCR Mesquite RDSPD

TEM McAllen RDSPD

TEN Tennessee School for the Deaf

TXF Texas School for Blind-Outreach

TXP Plano Regional Day School for the Deaf

TXS Five County Cooperative

TXV Victoria RDSPD

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ACKNOWLEDGEMENTS

Many people contributed to this annual INSITE data report and we wish to thank them. First of all, our sincere appreciation to Tom Clark, director of the SKI*HI Institute, and other Institute staff members for their wholehearted support. Next, our sincere thanks to the INSITE trainers for training new site personnel in data collection. Finally, and perhaps most importantly, we extend our most sincere appreciation to the children, parents, parent advisors, and administrators who participated in INSITE programming and data reporting.

INTRODUCTION

Project INSITE is a home intervention delivery model for families of sensory impaired children. The program service delivery system consists of: (1) identification/screening, (2) direct services in the home for handicapped children and their families, (3) support services (e.g., physical therapy, ophthalmological support services), and (4) a program management system. This report contains 1991-92 demographic and child progress data from 11 INSITE replication sites.

1.0 DEMOGRAPHIC INFORMATION

Table 1 illustrates demographic data on children participating in the INSITE program during the 1991-92 school year. Information was submitted on 132 children during this time period. The demographic data includes information on the following items:

1. Sex and Race
2. Frequency and Combinations of Handicaps
3. Type and Amount of Hearing Loss
4. Type of Visual Impairment
5. Visual Impairment Combinations and Specific Eye Disorders
6. Age of Suspicion and Identification of Hearing and Visual Impairments
7. Communication Methodology
8. Frequency of Home Visits and Other Services

1.1 SEX AND RACE

Table One indicates that 52% of INSITE children are female and 48% are male. A majority (72%) of the participants are Caucasian.

1.2 FREQUENCY AND COMBINATIONS OF HANDICAPS

As shown in Table 1, 101 (80%) of the INSITE children have a visual handicap. 91 (71%) are hearing impaired, 61 (48%) are mentally retarded, and 102 (79%) are physically impaired. Since INSITE children typically have more than one handicap, these percentages exceed 100%.

Regarding combinations of handicaps, the largest percentage of INSITE children (17%) have visual, hearing, mental, and physical handicaps. The next two largest categories are visual, hearing, and physical handicaps, and hearing and physical with 8% each.

1.3 TYPE AND AMOUNT OF HEARING LOSS

Table 1 shows the type of hearing loss and the degree of decibel loss for INSITE children who have a hearing impairment. Complete information was collected on 74 children, of whom 66% have sensorineural losses. Information on degree of hearing loss was collected on 68 children. The degree of unaided decibel loss is variable, ranging from 10 dB to 120 dB. The average unaided loss is 70 dB. The degree of aided loss ranges from 10 dB to 120 dB and the average aided loss is 51 dB.

1.4 TYPE OF VISUAL IMPAIRMENT

Information on the type of visual impairment is available on 78 INSITE children in Table 1. As presented, 47 children (60%) have an acuity loss; 43 (55%) muscle imbalance; 15 (19%) field loss and 40 (51%) visual processing disorder. The amount of visual loss was reported on 46 children.

1.5 VISUAL IMPAIRMENT COMBINATION AND SPECIFIC EYE DISORDERS

Table 1 shows that many INSITE children have combinations of visual impairments. 21% have an acuity loss and muscle imbalance, 20% have a processing loss. INSITE children also have a wide range of specific eye disorders. The most common specific eye disorder is cortical blindness (16%).

1.6 AGE OF SUSPICION AND IDENTIFICATION OF HEARING AND VISUAL IMPAIRMENTS

A major INSITE goal is early identification of vision and hearing handicaps. Early educational intervention is believed to maximize a child's development. In Table 1, data are presented with respect to visual and hearing handicaps. The suspicion of a

visual handicap occurs when the child is an average of 1.6 months of age; the average age of the child's visual loss is identified as 6.9 months. The average time lapse between suspicion and identification is 3.2 months. The suspicion of hearing loss occurs when the child is an average 2.5 months of age; the average age the child's hearing loss is identified is 11.5 months. The average time lapse between suspicion and identification is 4.8 months.

1.7 COMMUNICATION METHODOLOGY

When children and their families enter the program, the communication methodology is diagnostic and prescriptive. Thereafter, the children proceed through individualized communication training. As shown in Table 1, of those children whose data was reported on the older data sheets 71% are using signals and cues, 35% of the children are in the diagnostic category, 8% are using formal signs, 11% are using primitive signs, and 11% are using other types of communication methodologies. Of those children whose data was reported using the newer data sheet 82% are using cues, 43% are using gestures, 2% are using aided augmented devices, and 62% are using formal coactive signs.

1.8 FREQUENCY OF HOME VISITS AND OTHER SERVICES

Most of the INSITE children (73%) are visited once a week by INSITE parent advisors. In addition to their INSITE home visits, 62% receive educational services, 82% receive physical/occupational therapy, 40% receive speech/hearing therapy, and 36% receive medical/health services.

2.0 SUMMARY OF DEMOGRAPHIC CHARACTERISTICS: DESCRIPTION OF THE TYPICAL CHILD

The typical child (let's call her Jane) may have a combination of visual, hearing, and physical impairments. In the area of vision, Jane's type of loss is acuity loss and muscle imbalance. Her visual impairment was suspected at the age of 1.6 months and identified at 6.9 months. Jane's hearing loss is sensorineural and her unaided loss in

decibels is 70. The ages at which her hearing loss was suspected and identified were 2.5 and 11.5 months, respectively. Her current communication method is signals/cues. Jane is visited in the home once a week and receives a variety of non-INSITE services: physical/occupational therapy and educational services.

Table 1

Basic demographics for INSITE Children 1991-92

Demographic Characteristics	Frequency	Percentage	Number of Cases
Sex:			
Male	63	48	130
Female	67	52	
Race/National Origin:			
Caucasian	91	72	127
African American	21	16	
Spanish American	10	8	
Native American	1	1	
Other	4	3	
Frequency of Handicaps:*			
Visual	101	80	128
Hearing	91	71	
Mental	61	48	
Physical	102	79	
Emotional	8	6	
Learning	44	34	

*Because children may have more than one handicap, percentages exceed 100%

Table 1 (cont.)

Demographic Characteristics	Frequency	Percentage	Number of Cases
Combinations of Handicaps:			
Visual, Hearing, Mental, Physical	22	17	131
Visual, Hearing, Physical	10	8	
Hearing, Physical	10	8	
Visual, Physical	9	7	
Visual, Hearing, Physical, Learning	9	7	
Visual only	8	6	
Visual, Hearing, Mental, Physical, Learning	8	6	
Hearing, Mental, Physical	7	5	
Visual, Mental, Physical, Learning	7	5	
Visual, Hearing	6	5	
Hearing only	5	4	
Visual, Physical, Learning	5	4	
Visual, Mental, Physical	4	3	
Visual, Learning	3	2	
Visual, Mental, Physical, Emotional, Learning	3	2	
Hearing, Mental	2	2	
Visual, Hearing, Mental	2	2	
Visual, Hearing, Mental, Physical, Emotional	2	2	
Visual, Hearing. Learning	1	1	
Hearing, Mental, Learning	1	1	
Hearing, Mental, Physical, Learning	1	1	
Visual, Emotional, Learning	1	1	
Hearing, Mental, Physical, Emotional, Learning	1	1	
Visual, Hearing, Mental, Physical,	1	1	
Emotional, Learning	1	1	

Table (Cont.)

Demographic Characteristics	Frequency	Percentage	Number of Cases
Type and Amount of Hearing Loss (for 66 children with hearing loss):*			
Type:			
Sensorineural	44	60	55
Conductive	7	10	
Mixed	9	12	
Processing	6	8	
Sensorineural and Processing	2	3	
Sensorineural and Conductive	1	1	
Mixed and Processing	1	1	
Conductive and Processing	1	1	
Sensorineural and Mixed	1	1	
Conductive and Mixed	1	1	
All	1	1	
Type and Amount of Hearing Loss (for 66 children with hearing loss)(cont.):*			
Amount: Unaided (M = 70)			
No loss (0-24 dB)	3	4	68
Mile (25-44 dB)	12	18	
Moderate (45-64 dB)	13	19	
Severe (65-90 dB)	25	37	
Profound (90 + dB)	15	22	
Amount: Aided (M = 51)			
No Loss (0-24 dB)	1	5	
Mild (25-44 dB)	8	40	
Moderate (45-64 dB)	5	25	
Severe (65-90 dB)	4	20	
Profound (90 + dB)	2	10	
Type and Amount of Visual Loss (for 76 children with hearing loss):*			
Type:			
Acuity Loss	47	60	78
Visual Processing Disorder	40	51	
Field Loss	15	19	
Muscle Imbalance	43	55	

* Because children may have more than 1 type of reported loss, percentages exceed 100%.

Table 1 (Cont.)

Demographic Characteristics	Frequency	Percentage	Number of Cases
Type and Amount of Visual Loss (for 76 children with hearing loss):*			
Amount of Visual Loss:			
Reported as Visual Level:			
Totally Blind	2	7	28
Child sees a direct source of light (Level 1)	16	57	
Child sees shadows of objects blocking light (Level 3)	3	11	
Child sees movements, fixes/follows (Level 4)	3	11	
Child sees bright colorful toys or objects (Level 5)	2	7	
Child sees dull-colored objects with less distinctive features or contrast (Level 8)	1	4	
Child sees people's actions, routine daily events, different environments (Level 9)	1	4	
Reported as Snellen Acuity Equivalent			
20/20	1	6	76
20/50	1	6	
20/70	1	6	
20/150	1	6	
20/200	9	50	
20/300	1	6	
20/400	2	11	
20/450	1	6	
20/800	1	6	

Table 1 (Cont.)

Demographic Characteristics	Frequency	Percentage	Number of Cases
Type and Amount of Visual Loss (for 76 children with visual loss):*			
Visual Impairment Combination:			
Acuity, Muscle Imbalance	16	21	76
Processing only	15	20	
Muscle Imbalance only	8	11	
Acuity, Processing	8	11	
Acuity only	6	8	
Acuity, Muscle Imbalance, Field Loss	5	7	
Muscle Imbalance, Processing	5	7	
Acuity, Muscle Imbalance, Field Loss, Processing	5	7	
Acuity, Muscle Imbalance, Processing	3	4	
Acuity, Field Loss, Processing	3	4	
Acuity, Field Loss	1	1	
Muscle Imbalance, Field Loss, Processing	1	1	
Specific Eye Disorder:*			
Retinopathy of Prematurity	9	10	89
Strabismus	23	26	
Cataracts	6	7	
Optic Nerve Hypoplasia	8	9	
Cortical Blindness	31	35	
Refractive Error	6	7	
Glaucoma	2	2	
Optic Atrophy	10	11	
Retinal Detachment	3	3	
Other	43	48	

Demographic Characteristics	Frequency	Percentage	Number of Cases
Type of Communication Method:			
(Older data sheet)*			
Signals/Cues	30	71	
Diagnostic	13	35	
Formal Signs	3	8	
Primitive Signs	4	11	
Other	4	11	
(Newer data sheet)*			
Cues	52	82	
Gestures	19	43	
Aided Augmented device	1	2	
Formal Coactive Signs	35	62	
Frequency of Home Visits:			
Twice a Week	1	1	124
Once a Week	91	73	
Every Other Week	13	10	
Other	19	15	
Other Non-INSITE Services:*			
Educational	66	62	97
Physical/Occupational Therapy	87	82	
Speech/Hearing Therapy	41	40	
Medical/Health	38	36	
Mental	2	2	
Other	14	14	

* Because children may receive more than one service, percentages exceed 100%

Demographic Characteristics	Valid Cases	Mean
Average Age of Suspicion of Visual Loss	39	1.6 months
Average Age of Identification of Visual Loss	35	6.7 months
Average Time Lapse Between Suspicion and Identification for Visual Loss	28	3.2 months
Average Age of Suspicion of Hearing Loss	36	2.5 months
Average Age of Identification of Hearing Loss	46	11.5 months
Average Time Lapse Between Suspicion and Identification for Hearing Loss	29	4.8 months

3.0 DEVELOPMENTAL DATA

The developmental data includes a description of measures and data analysis and reporting procedures.

3.1 DESCRIPTION OF MEASURES

Children in the INSITE program receive regular testing on the Callier-Azusa Developmental Scale. The Callier-Azusa is composed of 18 subscales that are organized according to the following five developmental areas: Motor Development (MD); Perceptual Development (PD); Daily Living (DL); Cognition, Communication, and Language (CCL); and Social Development (SD). The scale is based on observation of the child's behaviors. Each child is observed for at least two weeks after which the scale is completed. After determining a child's raw score, developmental age equivalencies based on normal child development are recorded.

3.2 DATA ANALYSIS AND REPORTING PROCEDURES

An inherent problem in the analysis of progress of the very young is maturation. In analyses, it is difficult to "tease out" what is basic maturation and what is progress due to a given educational intervention. Two methods used to determine child progress in the INSITE program are the Callier-Azusa pre/post scores and Proportional Change Indices.

3.2.1 CALLIER AZUSA PRE/POST SCORES

One method for controlling for maturation is proposed by Sheehan (1979). He suggests the use of initial testing information as a means by which to predict a child's performance in the future. Using initial testing information, a child's developmental rate can be computed by dividing a child's initial developmental age by the chronological age. The post-intervention chronological age is multiplied by the developmental rate to determine a child's predicted score. For example, if a child has a pretest developmental age of 11 months and a pretest chronological age of 47 months, their developmental rate would be .23. Using the developmental rate, the child's predicted score is 12 when the

post chronological age is 52 months (.23 x 52). This predicted score thus becomes a standard against which to compare actual post-test information. The predicted score represents developmental change due to maturation alone; the actual score represents maturation and developmental change due to treatment. Ideally, the actual score should exceed the predicted score.

A summary of Callier-Azusa data for INSITE children during the 1991-92 year is shown in Table 2.

Table 2

Summary of Callier-Azusa Pre/Post Scores
1991-1992

	Motor Development (MD)	Perceptual Development (PD)	Daily Living (DL)	Cognition, Communication, Language (CCL)	Social Development (SD)
Mean:					
Pre	9.2	13.2	13.0	8.7	9.8
Post	11.4	16.8	16.0	11.6	13.2
Predicted	11.4	16.5	16.2	10.9	12.2
Did the actual post-score exceed the predicted score?	yes	yes	yes	no	yes
Number of Cases	52	52	52	52	52

As shown in Table 2, changes from pre to post are noted across all subtests. The degree of change ranges from 2.2 months for Motor Development to 3.6 months for Perceptual Development. What is particularly important is that all but one post-test values exceed predicted values. This indicates that INSITE children are scoring higher at post-test time than what would be expected due to maturation alone.

3.2.2 PROPORTIONAL CHANGE INDICES

INSITE scores on the Callier-Azusa are next transformed to Intervention Efficiency Indexes (Bagnato & Neisworth, 1980) and are compared against pretest developmental rates for each child in the program. The transformation ultimately yields a Proportional Change Index (PCI). The PCI, as described by Wolery (1983), compares children's rate of development during intervention to rate of development at pretest. The PCI equation is shown below:

$$\frac{\text{Developmental Gain}}{\text{Time in Intervention}} - \frac{\text{Pretest Developmental Age}}{\text{Pretest Chronological Age}} = \text{PCI}$$

Figure 1: Proportional Change Index

Children whose rates of development are slower during intervention than at pretest will receive a PCI of less than 1.0. In contrast, children whose rates of development accelerate during intervention will receive a PCI greater than 1.0. Ideally, one would want to see accelerated rates (i.e., greater than 1). Proportional Change Indexes, organized according to the five primary developmental areas of the Callier-Azusa Scale, for INSITE children are shown in Table 3.

Table 3

PROPORTIONAL CHANGE INDEXES FOR PROJECT INSITE CHILDREN 1991-1992

	Motor Development (MD)	Perceptual Development (PD)	Daily Living (DL)	Cognition, Communication, Language (CCL)	Social Development (SD)
N	51	52	52	52	52
Mean PCI	1.5	1.8	1.3	2.4	2.1

At a subscale level, the average PCI ranges from 1.3 for Daily Living, to 2.4 for Cognition, Communication, and Language. The average INSITE child shows accelerated growth during INSITE treatment in all developmental areas.

4.0 SUMMARY OF DEVELOPMENTAL PROGRESS: PROFILE OF THE TYPICAL INSITE CHILD

Recent assessment data show that our average child (Jane) improved in all areas of the Callier-Azusa Scale and that all but one post-test value exceeded what would have been expected in the absence of treatment. In general, Jane's overall rate of development improved during her INSITE intervention.

ERIC

REFERENCES

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Appendix E
Title Page/Contents for Products Developed in 1991-92

- Monograph: Working with Families of Young Children with Special Health Care Needs

- Resource Manual: Family Centered Intervention for Infants, Toddlers, and Preschoolers who are Visually Impaired

- INSITE Parent Resource Book

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WORKING WITH YOUNG CHILDREN WHO HAVE SPECIAL CARE NEEDS AND THEIR FAMILIES IN THE HOME

INTRODUCTION

General description of the population; who is serving them; the role early intervention people are playing in the home and why they should be involved as well as in what basic ways; statements about the distinct needs of these children and their families; the critcal need for a coordinated team approach amongst all caregivers involved; the kinds of intervention that may be appropriate. Just a good basic overview and statement of the need and how that is to be met by those of us in early intervention programs based out of educational settings or agencies outside of the medical community.

THE CHILDREN, THEIR MEDICAL CONDITIONS AND INTERVENTIONS

1. A Description of the Population: An introductory discussion of the numbers of children, the kinds of medical problems they have, why we see the increase in children with special health care needs, a bit of the background history, any future projections.

2. Specific Conditions and Their Interventions: In other words, basic information for the layman on each condition, prognosis, how it is treated, the special equipment used with diagrams and descriptions of how and what it is used for, its care, etc. For example, gastro tubes and tube feedings; tracheostomy and suctioning; respirators and ventilators, oxygen in the home...risks and care; catheters; shunts; ileo and colestomy; indwelling IV's; seizures and seizure medication; other information about medications; how child is transported when attached to various pieces of equipment.

3. Communicable Diseases: Basic information on each disease, treatment in young children, prognosis for the child's future, complications; how it is transmitted, carrier states; basic precautions and hygeine procedures to be taken by caregivers, particularily those who are pregnant; the need for the parent advisor to be healthy before going into the home. Diseases-CMV, Aids, Hepatitis B, MRSA staph infections, rubella.....

WHO ARE THE SERVICE PROVIDERS AND HOW CAN THEY WORK TOGETHER

1. ICU and NICU: What is it? What is it like? What heppens there? What is their role? How do parents feel about their experiences with it? Terms and definitions. How can early intervention interface with this service provider; build rapport with them? What do they want from early intervention?

2. The Child's Doctor, Other Specialists: Who are some of the types of physicians involved? How can early intervention best interface and develop rapport with them? How can we help them?

3. Home Health Care: What is it? What services does it provide? What is its role? How can early intervention best interface with them and build rapport. What do they want from early intervention?

4. Respite Care/Childcare: What is it and what is its role? How can early intervention assist parents in obtaining it as well as using it? What are the sources? How does early intervention interface with this service? Parent goes back to work, how do they get adequate childcare?

5. Other Support Services: What are they (ie. OT, PT, Speech)? How can early intervention assist parents in obtaining it as well as using it? What are the sources? How does early intervention interface with this service?

6. Early Intervention Programs: What are they? What are the ways they tend to be involved or can be involved? What is their role?

7. Insurance and Financial Support: What are the various sources parents can go to for financial assistance for medical costs, intervention, equipment, medicines and therapies? Listing of resources like Friends of Karen organization, etc. What does insurance most often cover? How can early intervention asssist parents in obtaining the help they need in this area?

8. Ways in Which the Service Providers Can Work Together to Serve These Children and Their Families: Case Management-who's role is it to lead the way? How can this best be done? Who are the critical members of the team? How do you get them to communicate, value each other and work together? Getting services like OT, PT, educational, even some of the daily medical care to happen in one location or as few locations as possible so that the parents are not running all over the place with the child. A truly collaborative IFSP or IEP.

PSYCHOLOGICAL ISSUES

1. Introduction: A brief overview of the psychological issues that are unique to this population and their families. A reminder of the need to understand the basic body of information about family systems with references on where to find that information. The need to know something about how different cultures deal with illness. Also some of the feelings service providers experience in working with this population.

2. Dealing with Repeated Hospitalizations, Setbacks, Regression: Parents' feelings; ways to help them cope; the need for sensitivty when doing progress updates during these times. How do service providers cope with this?

3. The Need for Normalcy in the Family Life and Routine: At what point does there get to be so many service providers in and out of the home that they no longer have private time? How the child's medical needs take over as the focus of family life and parental time. Loss of income when one parent quits a job or makes a job change so that they can help more in the care of the child at home. How can programs best work to encourage normalcy?

4. Dealing With the Death of the Child: How this mourning and grieving process may be different from that of parents dealing with a handicapped child who is expected to live (there is closure in death). How different cultures and belief systems handle it. References for resource materials and organizations such as Compassionate Friends or Hospice. Role of early interventionist during and after the funeral(ie. perhaps attend funeral, take food to the home, notifying other agencies, being there afterwards to talk about the child who is still on the

parents' mind; concerns about paying for the funeral; unresolved family conflicts that might arise during this time of stress and loss) The siblings feelings. The Parent Advisors feelings.

5. Other Family Members: Needs/Feelings of siblings; grandparents. Ways to assist them. Resource materials to use with them.

THE ROLE OF THE PARENT ADVISOR IN PROVIDING EARLY INTERVENTION SERVICES TO THE HOME OF THE CHILD WITH SPECIAL HEALTH CARE NEEDS

1. What is the Role of the Parent Advisor? What should she do (ie. provide information and support; listen; help with coordination of services; work as a member of the service team; assist with appropriate developmental assessment, goal setting, program planning and progress update for the IFSP; provide stimulation ideas that realistically fit into the normal family routine, with the families priorities at this time and the child's state of health)? What should she not do (ie. carry out the medical procedures...to what extent; act like the expert....)? With some families, may need to help them understand that their special child needs a special doctor. Not any old doctor will do. May need to help get them in touch with people who can help point them in the right direction as it relates to certain medical problems. Assist them in becoming more comfortable with their doctors if they feel intimidated and are not free to ask questions and share their observations/concerns.

2. Assessment, Setting Goals, Updating Progress: Basic ideas on how to do this. Tools to use (ie. developmental tools, behavior state observation methods...).

3. Working in the Home: Be very respectful of the need for privacy and normalcy; don't overload; take a back seat; parent should drive the system as much as is possible; if parents are not comfortable with the medical procedures, encourage them to ask for questions and more training in doing them from their doctor, nurse, etc.; assisting in the communicaton between medical people and the home if there is a breakdown in understanding. Realize that it may be hard to maintain continuity in the home programs due to repeated hospitalizations and illness. Use normal routines. Ways to use home health care and respite care workers to provide appropriate stimulation activities

when the child is alert and wanting to interact and play. Be sensitive to the child's health. If you have a cold, or could possibly be carrying a virus, don't make your home visit. Reschedule for when you are well. Likewise, when working with child with a communicable disease, be very conscious of using good hygeine procedures. If you are pregnant or otherwise have very strong concerns that interfere, you may need to ask that someone else work with this child and family. You have to be comfortable with the situation you are working in. Showing parents ways to organize all information they get, medical records, reports, discharge summaries if they don't already do this so that they can easily find what they need. Also, how to keep a log of their thoughts and events. PA's role in observation of behavior (ie. seizures, affects of medications) and helping parents do this, if needed.

3. Working Directly With the Child: Learn from the parents, medical staff and child what types of intervention he can tolerate and for how long. When is he alert? What does he like? What do parents want him to learn? Work for short periods of time. Keep it simple. What positions can be used with him? Refer to Developmental Activities Section of this monograph for specific ideas and adaptations.

3. Working With the Family During Periods of Hospitalization: Must be flexible. With some families, PA may need to encourage them to take the child to his own doctor right away and not wait until he is so ill that they have to rush him to the emergency room to be seen by strangers. Some parents may need additional help in learning to recognize signs of trouble. Once in the hospital, if OK with the parent, the PA could make visits there. Interact with the medical staff. Learn from them. Teach them how to incorporate cueing when doing medical procedures. Perhaps, stay with child for a couple of hours to give parents a break; PA could keep in touch by phone. Offer support through listening, responding to requests with ideas and information, etc.

4. Assisting With Transition: As child gets old enough to be in a center based program, the issue of whether he should or should not attend one may come to the family's attention. How can the PA help with information? Assist parents in looking at and exploring the possibilities and pros and cons. Some very ill children may need to stay homebound. What is the perspective of his doctors and their concerns? If the parents make the decision to put the child in the preschool program, then how

can we help them gradually make that change? How will the medical procedures be taken care of; who will do it; if training is needed, who will do it; how will medical needs and procedures be monitored; what is the parents role? How can the other preschool children in the class be prepared for this new child with special health care needs?

5. Liability: What precautions should the parent advisor take in the home as she handles and works with the child? Does she need special insurance? What do the parents need to do for "reasonable care". For example, some parents have been brought into the courts for the death of their child who was medically fragile. What are the parents' rights for privacy as it relates to medical records.

DEVELOPMENTAL ACTIVITIES ADAPTED FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Note: These are examples of activities in each area that promote normalcy in the family routine and home. This is not to be an exhaustive list. The activities should be adapted for the child who is technologically dependent or medically fragile as well as appropriate for this population. The activities should be written in the following format.

Activity: (Name it in a few brief words.)
Purpose: (Briefly state what the activity is for or why you do it.)
Who: (Briefly describe the level/type of child it is most appropriate for, ie. infant, toddler; child who is not mobile at all verses one who can move on his own some; very ill child verses one who is feeling well.)
Materials: (Briefly list toys, equipment, materials needed. Include any diagrams/sketches that would be helpful.)
What to do: (In list format, ie. 1, 2, 3....., describe the steps or how to do the activity. Be sure to include a description/sketch of the position to use and any communication cues (object, touch, cue, word) important to use during the activity.)
Responses: (If appropriate, briefly describe the response you would like to see out of the child. You may wish to note what some un-desirable responses might look like and how to respond, adapt or change the activity accordingly.)
Other: (Note any other suggestions or adaptations needed here.)

AREAS

1. Daily Care: Feeding-tube fed children, how to provide oral stimulation (nipple on end of vibrator), how to develop olfactory and gustatory senses (swabs dipped in flavors and put on their lips or in the mouth); aspiration; caring for the teeth; how to bathe, dress and undress when attached to medical equipment; toileting; providing infant massage. Simulation: one mother asked that the nasogastro tube be put down her throat so she would know how it might feel to her child....as a result, she now does the procedure as smoothly and quickly as she can so as not to prolong it. Use songs and games during routine care to make it more pleasant and fun.

2. Communication/Social: Special cues, signals and coactive signs to use for the equipment and invasive medical procedures (ie. tap nose before put in nasogastrotube; use mask or piece of tubing as object cue for suctioning. How do we tone down the unfriendly environment of the hospital with its hurts, pokes, weird noises, strange faces? Post trache voices. Other special communication systems or devices. Turn-take games.

3. Gross Motor/Mobility: Types of positioning equipment that can be used (ie. tumbleform chair in bed helps with upright position). Ways to position and handle the child (ie. sidelying); use what exists in the home to position the child. Diagrams and patterns for equipment. Be sure to remove the child from bed to work to allow a change of environment and aid in better handling. How to work on gross motor skills depending on what the child is attached to. Adapt strollers to hold portable machines (ie. oxygen, suction machine) so that the child can be taken outdoors).

4. Play (Leisure) and Hand Skills: Good positions for play and ideas for play activities (ie. a little girl who really got into manipulating and exploring tubing and the decorative shoelaces used to tie her equipment together). If medically OK, the benefits of going outside. Hang toys on the inside edge of the crib/bed so they don't dangle and get in the way of the medical equipment. Hook up battery operated swith toy to bedside in reach of the child.

5. Sensory Stimulation: Positions that help the child use what vision and hearing he already has. Hang mylar balloons and wind sock from IV pole. A new crib toy to use at home or in the hospital that generates a "sh-h" sound when things get to noisy. Need of child to hear parents' voice while in the hospital. "Bopper" toys are good for auditory. Play music tapes certain times of the day for child to listen to. Provide a lot of touch. Give massages.

RESOURCES

(National Agencies, reading material, media to view....)

RESOURCES FOR FAMILY CENTERED INTERVENTION FOR INFANTS, TODDLERS, AND PRESCHOOLERS WHO ARE VISUALLY IMPAIRED

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Appendix F

New INSITE Training Format

INSITE Workshop #1, New Format

Day One

9:00	Welcome and Agenda
9:30	Background and Rationale for Home Intervention
9:45	Overview of INSITE Model
10:15	Break
10:30	Transdisciplinary Teaming Practicum (optional)
11:00	What is a Parent Advisor
11:30	Lunch
12:30	Working With Families/Practicum
2:00	Break
2:15	Family Focused Interview
3:00	Who is the MHSI Child?/Simulation Experiences
4:15	Dismiss

Day Two

9:00	Overview of INSITE Curriculum Planning, Delivering, Reporting, Getting Started
9:30	Overview of Communication & Cognition Programs
10:00	Break
10:15	Creating and Environment That Fosters Communication
11:30	Lunch
12:30	Informal Communication
2:45	Break
3:00	Formal Communication and Coactive Signing (brief overview)
3:30	Overview of Hearing Program
4:00	**Assignment Overnight:** Look over the portion of the INSITE checklist your group was assigned
4:15	Dismiss

Day Three

9:00	Overview Motor Program
9:30	Overview Vision Program
10:00	Break
10:15	Developmental Assessment of Child/INSITE Checklist
11:00	Questioning Strategies for Gathering Information About the Family (ie. Resources, Supports, Concerns, Priorities and Goals) Needed for the IFSP
11:30	Getting Ready for Practicum with a Child and Family
12:00	Lunch
1:00	Assessment, Goal Setting and Program Planning with the Child and Family
3:00	Prioritize Needs for WS#2, Complete Learning Activity Agreement for trainer, Fill out workshop evaluation Plan contents of Workshop #2 together
3:30	Time with Local Supervisor or INSITE Contact Person
4:00	Dismiss

INSITE Workshop #2, New

Potential Topics

Hearing and Auditory Programs- one day

Vision and Vision Programs- one day

depending on background of group the sensory material could be done in split sessions (ie. people with hear background are with 1 trainer getting vision and those with vision get hearing with other trainer)

Motor Impairments, Daily Care- one day

Preschool Orientation and Mobility- worked into motor day for 1-2 hours, meaning motor and daily care would need to be cut a little

Tactile & Braille Readiness-- 1-2 hours

Cognition-2 hours

Social Skills and Behavioral Issues- 1-2 hours

Discussion on Cultural Issues and How to Adapt INSITE to the different types of families they encounter locally

Teamwork and Networking with Each Other

INSITE Overview for Administrators and Support Staff

Appendix G

Summary of Awareness Conference Evaluations

SKI*HI/INSITE NORTH CENTRAL REGIONAL CONFERENCE
CONFERENCE EVALUATION RESULTS

SITE: ST. PAUL, MINNESOTA
DATE: JULY 30 - AUGUST 1, 1992
RESPONDENTS: 29

QUESTION	RAW SCORE	PERCENTAGE
1. Compared to other conferences I have attended, this workshop is in the:		
Top 10%	15	52%
Top 25%	11	38%
Middle 30%	3	10%
Bottom 25%		0%
Bottom 10%		0%
2. The information I received at this conference will be useful to me in my work:		
Strongly Agree	18	62%
Agree	11	38%
Neutral		0%
Disagree		0%
Strongly Disagree		0%
3. This conference met my expectations:		
Strongly Agree	15	52%
Agree	13	45%
Neutral	1	3%
Disagree		0%
Strongly Disagree		0%

Comments:
- EXCEEDED expectations

4. Based on this conference, I would attend another North Central Regional SKI*HI/INSITE Conference:		
Strongly Agree	23	79%
Agree	6	21%
Neutral		0%
Disagree		0%
Strongly Disagree		0%
5. I had enough information about this program before I arrived:		
Yes	20	69%
No	6	21%
Yes/No	3	10%

Comments: GREAT!

- Yes, after registering. No, before registering
- Would have liked conference agenda sent with confirmation letter
- Agency in-house problem, info was probably there, but not distributed
- Format changed from original, was okay, just different.
- Too late
- Late in coming

6. **If I answered *NO* to #5 above, I have written my comments next to those items for which I required additional information:**

(1) Registration
- Late
- Perhaps a contact person such as Foundation for Better Hearing & Speech, Cheryl McMann or Dept. of Education, Larry Krouse, would have a mailing list for this area.
- What was scheduled, what was offered, didn't get this info 'till I got here.
- History of SKI*HI, what materials are available at our agency, SKI*HI's involvement in our geographical area. Was explained through sessions, however.

(2) Lodging/Food Service
- Great (2), sharing a bathroom in the dorm brought back memories
- Great food (6), enjoyed variety
- Late
- Meals were wonderful
- Good food (4), could have scheduled so students weren't in line at same time
- Need cleaner showers
- Lodging was okay, "dorm fine!"(2)
- Food serving time too short, especially barbeque, I missed it! (NOTE: No, this wasn't Donna)

(3) Location/Facility
- Needed a map ahead of time for directions and distance from airport
- Super
- Excellent, beautiful area (4), not much time to explore
- Beautiful setting, comfortable facilities, easy to find
- Great (5)
- Nice, good

(4) Other:
- Great weather

Comments:

- Send info earlier, mine received after school was out

7. **I thought the following were the best aspects about this conference:**

- Speakers were excellent, everyone very knowledgeable in their areas, times were appropriate, location great, food yummy. Liked a summer conference. SKI*HI staff helpful and wonderful (2). It was a HUGE success.
- Planning for future conference, HIV info
- Renewed motivation/challenge (2), intensive/effective conference time management
- Good speakers, diverse topics, asking for topic interest before conference, time to meet with colleagues
- Multi-handicapped session--Actually, all the sessions
- Behavior, Crackerbarrel, home visit activities
- Rock Soup (5), Jo Mascorro (6), Parent Panel (11)
- Meeting people, people were fun to be with
- Presenters were good and covered a wide range, session lengths were good (2), cost was affordable
- People were friendly and talkative, comfortable/relaxed atmosphere, received useful information and suggestions
- Interaction with colleagues, other PA's (4)
- Great variety (2)
- Enjoyed Debbie Lively - great presentation
- Audience comments
- Upbeat, good adherance to schedule, quality and competency of presenters, friendly and approachable SKI*HI staff, current/relevant issues, variety of topics, crackerbarrel promoted sharing of information
- Door prizes
- Excellent program, choice of presentations
- More basic info on SKI*HI/INSITE for those of us who don't belong
- Extremely well organized for participants, wonderfully organized
- Relevant information, dynamic speakers

8. **I think the following things could be done to improve this conference if offered again:**

- Administrator's meeting conflicted with concurrent sessions (2), SKI*HI Staff meeting was "blah!"
- Home towns/work area/program of participants printed on name tag (3), repeating popular sessions so they won't be missed because of interest conflict (6), a balance of parents using TC and aural-oral communication on the parent panel.
- Get input from SKI*HI/INSITE users as to frequency of conferences (more often as this was VERY GOOD), have some sessions offered twice
- Little more break time
- More information about St. Paul's evening activities (2)
- Better advertising
- Better pre-conference publicity, maybe through state dept. mailings or ECSE coordinators. I kept thinking of people I wished had been here as several sessions would have easily fit their needs, but they had no connection with the program (SKI*HI/INSITE) and weren't informed.
- Get more to attend

- Would be nice to have deaf parents on the Parent Panel
- Try to get more PA's involved
- Different time of year, perhaps teacher ed. days (mid-October)
- More small group settings with a "topic" discussion, not crackerbarrel
- Avoid presentation/discussion during lunch
- Clearer designation of emphasis of presenter (hearing/vision/deaf-blind)
- State presenter's credentials and current professional assignment in session description.
- Start breakfast and first meeting later
  8:30 - 9:00 Breakfast
  9:15 - Meetings begin
  Get more comfortable seating, adequate # of interpreters

Additional Comments:

- Thanks for all the efforts to organize a wonderful workshop (2)
- You really did a great job, not much room for improvement!

Appendix H

Summary of Evaluations of North Central Regional Conference, 1992

SKI*HI/INSITE NORTH CENTRAL REGIONAL CONFERENCE
CONFERENCE EVALUATION RESULTS

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